"Low back pain, quality of life and function in people with incomplete spinal cord injury in USA, UK and Greece"

A thesis submitted for the degree of Doctor of Philosophy

by

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Abstract

Background: Pain is a common consequence of Spinal Cord Injury (SCI). While research into pain in SCI is vast, examining musculoskeletal pain (MSKP) and low back pain (LBP) are limited. This thesis aims to investigate these categories of pain in incomplete SCI (iSCI). The experience of pain is known to affect quality of life (QoL) and function. The impact of the experience of pain, particularly of LBP, on both the QoL and function are examined in this research. While research in similar fields is predominantly conducted in single nation populations this research is set out to study three different nations.

Method: The following were part of this study:

- A systematic literature review on the prevalence on chronic back pain (BP), LBP and MSKP in SCI.

- A translation, and preliminary validation, into Greek of the Spinal Cord Independence Measure (SCIM version III).

- A cross-national survey conducted in the USA, UK and Greece. Questionnaires included the short-form McGill Pain questionnaire (SF-MPQ), EQ-5D and the SCIM III. They were collected either online or via post and 219 questionnaires were analysed.

Results: The papers included in the systematic literature review were considerably heterogeneous not allowing meta-analysis to be made. 95% confidence intervals (CI) for the total number of participants in the studies were used. Among people with pain the prevalence of chronic MSKP (CMSKP) was 49% (95%CI 44%, 55%), of chronic BP (CBP) was 47% (95%CI 43%, 50%) and chronic LBP (CLBP) was 49% (95%CI 44%, 55%).

GR-SCIM III maintains its unidimensionality and has acceptable internal consistency (α=0.78). Concurrent/criterion validity for the two cross-examined subscales were strong for "self-care" (ρ=-0.78) and moderate for "mobility" (ρ=-0.58). Unidimensionality was also confirmed for the English version of SCIM III, which had accepted internal consistency (α=0.79) and strong concurrent/criterion validity for "self-care" (ρ=-0.75) and moderate for "mobility" (ρ=-0.45).

The survey results showed that the prevalence of current LBP is 67.9% (95%CI 61%, 73%) and of MSKP is 38.8% (95%CI 32%, 45%). LBP was of moderate intensity and most commonly described as "aching". People who report pain, LBP or MSKP reported worse QoL. The impact of LBP on QoL was greater than that of pain in general or MSKP. The increased intensity of LBP correlated with worse function. Among the three participating countries, people from the UK had the worst experience of pain and LBP, classified themselves with the worst health status and reported the worst functional independence.

Conclusion: This study offers the first systematic review on CLBP, CBP and CMSKP in SCI. It is unique in using SCIM III by self-report and into Greek. The results show that LBP is highly present in iSCI affecting both QoL and function. Both the GR-SCIM III and the SCIM III are reliable for use, however studies are needed to examine further their psychometric properties. The findings of the study fit with features of the currently used patients' rehabilitation models.

Ithaca (translated in English)

As you set out for Ithaca
hope your road is a long one,
full of adventure, full of discovery.
Laistrygonians, Cyclops,
angry Poseidon - don't be afraid of them:
you' ll never find things like that on your way
as long as you keep your thoughts raised high,
as long as a rare excitement
stirs your spirit and your body.
Laistrygonians, Cyclops,
wild Poseidon - you won't encounter them
unless you bring them along inside your soul,
unless your soul sets them up in front of you.

Hope your road is a long one.
May there be many summer mornings when,
with what pleasure, what joy,
you enter harbours you're seeing for the first time;
may you stop at Phoenician trading stations
to buy fine things,
mother of pearl and coral, amber and ebony,
sensual perfume of every kind -
as many sensual perfumes as you can;
and may you visit many Egyptian cities
to learn and go on learning from their scholars.

Keep Ithaca always in your mind.
Arriving there is what you're destined for.
But don't hurry the journey at all.
Better if it lasts for years,
so you're old by the time you reach the island,
wealthy with all you've gained on the way,
not expecting Ithaca to make you rich.

Ithaca gave you the marvellous journey.
Without her you wouldn't have set out.
She has nothing left to give you now.
And if you find her poor, Ithaca won't have fooled you.
Wise as you will have become, so full of experience,
you'll have understood by then what these Ithakas mean.
Konstantine P. Kavafis (1911)[1]

Ιθάκη (original in Greek)
Σα βγεις στον πηγαιμό για την Ιθάκη,
να εύχεσαι νάναι μακρύς ο δρόμος,
γεμάτος περιπέτειες, γεμάτος γνώσεις.
Τους Λαιστρυγόνας και τους Κύκλωπας,
τον θυμωμένο Ποσειδώνα μη φοβάσαι,
τέτοια στον δρόμο σου ποτέ σου δεν θα βρεις,
αν μέν' η σκέψις σου υψηλή, αν εκλεκτή
συγκίνησις το πνεύμα και το σώμα σου αγγίζει.
Τους Λαιστρυγόνας και τους Κύκλωπας,
τον άγριο Ποσειδώνα δεν θα συναντήσεις,
αν δεν τους κουβανείς μες στην ψυχή σου,
αν η ψυχή σου δεν τους στήνει εμπρός σου.

Να εύχεσαι νάναι μακρύς ο δρόμος.
Πολλά τα καλοκαιρινά πρωιά να είναι
που με τι ευχαρίστηση, με τι χαρά
θα μπαίνεις σε λιμένας πρωτοειδωμένους·
να σταματήσεις σ' εμπορεία Φοινικικά,
και τες καλές πραγμάτειες ν' αποκτήσεις,
σεντέφια και κοράλλια, κεχριμπάρια κ' έβενους,
και ηδονικά μυρωδικά κάθε λογής,
όσο μπορείς πιο άφθονα ηδονικά μυρωδικά·
σε πόλεις Αιγυπτιακές πολλές να πας,
να μάθεις και να μάθεις απ' τους σπουδασμένους.

Πάντα στον νου σου νάχεις την Ιθάκη.
Το φθάσιμον εκεί είν' ο προορισμός σου.
Αλλά μη βιάζεις το ταξίδι διόλου.
Καλλίτερα χρόνια πολλά να διαρκέσει·
και γέρος πια ν' αράξεις στο νησί,
πλούσιος με όσα κέρδισες στον δρόμο,
μη προσδοκώντας πλούτη να σε δώσει η Ιθάκη.

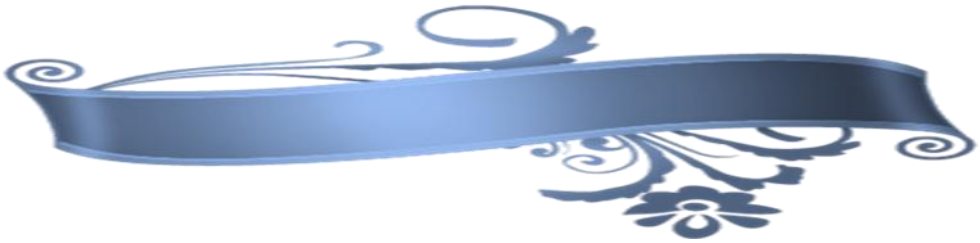
Η Ιθάκη σ' έδωσε τ' ωραίο ταξίδι.
Χωρίς αυτήν δεν θά βγαινες στον δρόμο.
Άλλα δεν έχει να σε δώσει πια.
Κι αν πτωχική την βρεις, η Ιθάκη δεν σε γέλασε.
Έτσι σοφός που έγινες, με τόση πείρα,
ήδη θα το κατάλαβες η Ιθάκες τι σημαίνουν.
Κωνσταντίνος Π. Καβάφης (1911)

[1] Kavafis (1863-1933BC) was a Greek poet who mainly lived in Alexandria of Egypt. He is considered to be one of Greece's and Europe's elite modern poets. The poem "Ithaca" was inspired by the return journey of Odysseus back to his home island, as described by Homer; a journey that lasted 10 years and was full of adventures.

Dedications

This thesis is dedicated to my mother, Soultana, because no matter what the challenges in life are, her love is unconditional.

This thesis is also dedicated to my father Dimitris, who along with my mother made it a purpose of their lives to help their children follow their educational and professional desires.



Αφιερώνετε στην μητέρα μου, Σουλτάνα, που παρόλες τις προκλήσεις στη ζωή, η αγάπη της είναι άνευ όρων.

Αφιερώνετε, επίσης, στον πατέρα μου Δημήτρη, ο οποίος μαζί με τη μητέρα μου έκαναν σκοπό της ζωή τους να βοηθήσουν τα παιδιά τους ν'ακολουθήσουν τις ακαδημαϊκές και επαγγελματικές τους επιθυμίες.

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with the owners of various SCI websites who approved of the study being posted, made the distribution of the electronic version of the survey possible.

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List of abbreviations

ASIA= American Spinal Injury Association
BP= Back Pain
CBT= Cognitive Behavioural Therapy
CBP= Chronic Back Pain
CDSMP= Chronic Disease Self-Management Program
CI = Chief Investigator
CI= Confidence Interval
CLBP= Chronic Low Back Pain
CMSKP= Chronic Musculoskeletal Pain
CPGQ= Chronic Pain Grade Questionnaire
d= Cohen's d (effect size)
DV=Dependent Variable
DVT =Deep Venous Thrombosis
EDA= Exploratory Data Analysis
EPHPP= Effective Public Health Practice Project
EPSRC= Engineering and Physical Sciences Research Council
EQ-VAS= Visual Analogue Scale used in EQ-5D measure
ES=effect size
ESCIF: European Spinal Cord Injury Federation
F (test) = One-way ANOVA
FIM = Functional Independence Measure
GLM= General Linear Model
GPD= Gross Domestic Product
GR-SCIM III= Greek (GR) version of Spinal Cord Independence Measure (version III)
H test= Kruskal-Wallis H test
HRQoL= Health Related Quality of Life
IASP= International Association of the Study of Pain
ICF= International Classification of Impairment and Disability
IP= Internet Protocol
iSCI= Incomplete Spinal Cord Injury
ISCIPDS:B= International Spinal Cord Injury Pain Basic Data Set
IT= Information Technology
IV= Independent Variable
KMO test= Kaiser-Meyer-Olkin test
K-S test= Kolmogorov-Smirnov test
LBP = Low Back Pain
LF-MPG= Long-form McGill Pain Questionnaire
MCSD= Minimum Clinically Significant Difference
MPI= Multidimensional Pain Inventory
MPQ = McGill Pain Questionnaire
MSKP= Musculoskeletal pain
MTD = Multidisciplinary
NHS- National Health Service
NHST= Null Hypothesis Significance Testing

NRS= Numeric Rating Scale
NSCIA= National Spinal Cord Injury Association
p= p value (alpha level; α-level)
PCA= Principal Component Analysis
PDA= Personal Digital Assistant
PHC= Primary Health Care
PhD= Doctor of Philosophy
PI= Principal Investigator
PPI= Present Pain Intensity
PRI= Pain Rating Index
QoL = Quality of Life
r= Pearson's correlation
RR = Response Rate
RTA = Road Traffic Accident
SCI = Spinal Cord Injury
SCIM III = Spinal Cord Independence Measure (version III)
SCIMS= Spinal Cord Injury Model Systems
SF-MPQ = Short-Form McGill Pain Questionnaire
SHSSC = School of Health Science and Social Care
SIA = Spinal Injury Association
TEI: Technological Educational Institution
t-test= Student's t test
U test= Mann-Whitney U test
UK = United Kingdom
USA = United States of America
VAS = Visual Analogue Scale
WHO= World Health Organisation
WHOQOL-BREF= World Health Organisation QoL-BREF
WWW= World Wide Web
α= Cronbach's alpha
γ= Gamma test
η^2= Eta-Squared (effect size)
ρ= Spearman's rank correlation rho
ϕ= Phi test
χ^2= Chi-Square test
ω^2= Omega-squared (effect size)

Chapter 1; Introduction

Chapter Brief Table of Contents

"The beginning is the most important part of the work"
Plato (428/427 BC – 348/347 BC) - Greek Philosopher

1.1 Introduction

The research described in this thesis examines the experience of pain for people with incomplete spinal cord injury (iSCI). Pain is one of the most commonly reported problems for people with Spinal Cord Injury (SCI) and one which has negative consequences for their lives. Because the boundaries of this research field are extensive, it should be stated that the emphasis of this project is to examine the presence of low back pain (LBP) in this population. Further, it seeks to understand how the experience of pain relates to both the quality of life (QoL) and function of the person with the injury.

This chapter is an overview of the study to be presented which will set the context of the study, explain the reasons for and the significance of conducting it, as well as stating how it may contribute to what is already known in the field. Emphasis will be placed on the main aim and objectives of this research and the chapter will conclude with a description of the thesis formation.

1.2 Research rationale and setting

Disability, which is part of the human condition, is believed to affect the lives of 15% of the world's population and the number of people with a disability is growing.[499] The reasons for this increase include an ageing population and technological advances that help to keep people alive. As life expectancy has increased over the last century for people who sustain SCI,[53,499] emphasis is now placed on improving the QoL of a person living with any form of disability or impairment. Disability increases societal costs both via direct health-related expenses and incapacity benefits[260] and the cost of SCI is very high.[24,113]

The impact of the disability is primarily a challenge for the patient him/herself who has to adjust to a routine that often has, in the case of SCI, a sudden and violent onset. Living with a disability can impact negatively on the QoL and mental health of the patient, which can be compounded by factors like unemployment[260] or social factors.[111,254] QoL is also reduced by the presence of pain.[12,22,55,90,103,186,240,406,422,489] Pain also interferes with activities and function,[90,381,427,469] thus adding another

challenge to the daily routine of the person. It is not just the presence of pain that needs to be considered when thinking about QoL or function but also the intensity of pain as increased pain intensity is linked to increased catastrophising, depression, distress, reduced QoL[15,51,257,370,387,450] and leads to decreased levels of activity.[228] These factors give a clear indication of the complexity and the interaction between the psychological, physiological and the pain experience in cases of impairment and disability, including SCI.

Pain has been studied possibly more than any other symptom in the literature over many centuries. The reason for this is probably because it is experienced as a negative sensation and emotion that accompanies the vast majority of physiological and/or psychological ill health, impairment and disabilities. Despite the multitude of papers written about pain and the huge progress made in understanding it, it still remains a rather elusive area that raises debate on its origin, its impact and its treatment. Pain is a subjective experience as felt and reported by the patient. It is also a multidimensional experience according to the most recent theory,[306,308,309] which explains why it has been so difficult to understand pain. For many years researchers have been studying pain via examining groups of patients with the same condition, for example, studying pain in SCI. This may have developed from the need to understand pain in the hope of identifying similar pain characteristics as reported by people who have similar health problems. This approach has been successful as it seems that people who come from the same patient group describe their pain in a similar way. Thus studying a single condition, here SCI and in particular iSCI, is an appropriate step towards understanding pain.

The prevalence of pain in SCI is frequently reported to be high often exceeding 70%.[58,317,331,380,381,451,489] Consequently, the wealth of research available for this patient group is justifiable. This research into pain in SCI has helped not only with the development of a particular language when referring to pain in this population, but also in identifying directions which research should follow and gaps that need to be filled. It is becoming more apparent that research should move away from examining pain in general and consider examining specific types or locations of pain. As such, in

the SCI literature, studies have examined particular aspects of pain but there is a tendency to focus on neuropathic pain or, when reporting on specific locations, the focus tends to be on the shoulder or the upper limbs.[7,92,196,322] Certainly information gained so far has been most valuable in understanding pain in SCI, but there are other pain categories than need to be addressed in more detail. Two that this study will seek to explore are musculoskelatal pain (MSKP) and low back pain (LBP). MSKP has been addressed in SCI fairly often when referring to pain in areas like the shoulder or when discussing pain classification.[19,58,381,406] However, this study will seek to explore MSKP in more detail in relation to QoL and function. LBP is one of the two most common causes of disability in Western society[238] with millions of GP visits[11] and high reported prevalence (ranges from 12% to 49%) [107,248,263,346] in the general population. Although it is a pain location commonly seen, it is not examined for people with SCI who may be more vulnerable to developing LBP.

As it can happen with any pain type and probably pain location, LBP can be disabling, having a negative impact on the lives of people living with it. Indeed, people from the general population who have LBP, which is often of musculoskeletal origin, risk having recurrent episodes of it[88,348] increasing the likelihood of it becoming chronic as well as increasing the socio-economic impact.[107,280] The experience of pain is known to affect the QoL of the person living with pain. In both the general population but also when there are other health problems, such as SCI, pain negatively affects mood, is associated with anxiety or depression and with an overall reduction in QoL.[12,49,219,230, 288,331,235,362,366,409,481, 498] There does not appear to be specific information on the impact of LBP on the psychological health or the overall QoL of people with SCI, whereas related information about the general population and other patient groups is gradually emerging.[215,330,439,496,498] The negative relation between pain and function, including for people with SCI, has also been reported.[94,362,446,496,498] The relation between LBP, in particular, and function in SCI has not been examined.

From anecdotal sources, and personal communication with doctors and other health professionals, the problem of back or lower back pain in SCI is not uncommon: however, there is lack of published research into understanding its origin and

consequences. These identified gaps in the field of SCI, could have a significant effect on the lives of people with SCI. A lack of awareness can lead to underreporting of a problem, reducing appropriate assessment and not implementing treatment in a timely manner. It is, therefore, essential when studying location of pain in SCI to include the lower back in the areas examined and not solely the whole back, which is now gradually being investigated.[90,380,381,457]

Research in the above fields, but also in other related fields in the literature, has been predominantly done by examining populations from a single nation. More recently, cross-national, cross-cultural or international research has increased rapidly. Globalisation, the ease of transport between countries and technological developments, both demand and facilitate the conduct of such studies. Among the benefits of cross-national research is the fact that it raises questions about single-nation studies and it forces revisions and interpretations of results because of the differences found between countries.[245] A number of single-nation studies have investigated pain, MSKP or LBP in the general population[11,35,59,75,128,132,157,192,358,417,424,460,475] and in the SCI population.[80,145,228,284,380,427,450,451,457,484] But the number of cross-national studies looking at pain, MSKP or LBP in the general population and in the SCI population is considerably less.[38,121,182] This is also noticeable when examining QoL or function, particularly in SCI, as cross-national studies are limited.[64,171,255]

There is no doubt that a better understanding of the experience of pain and how this impacts on other aspects of patients' lives requires that researchers investigate the different categories and locations of pain. Melzack et. al[305] quoted their early work with Casey saying that pain is a subjective, personal experience with psychological dimensions,[307] which can be affected by personal and cultural factors, thus cross-national studies become an appropriate and effective way to understand pain better. This is exactly what this study aims to investigate.

1.3 Research aim, objectives and hypotheses

The core *aim* of the study is:

> *To study LBP in people with iSCI, in USA, UK and Greece, and to investigate what is the present and usual pain experience and how it relates with quality of life (QoL) and function.*

The core *research question* of the study is:

"Do people with iSCI have LBP, and what is their present and usual pain experience?"

In addition LBP, pain in general and MSKP will be explored and examined in relation to QoL and function.

Seven objectives have been developed as an appropriate method to address the aforementioned aims:

Objective 1: To explore the research background that will assist in guiding the development of the elements to be included in the project. To focus on pain at the lower back location and to investigate QoL and function.

Objective 2: To carry out a survey in order to report on the prevalence of LBP, MSKP and pain for the total group and each national group. In addition, to investigate differences and similarities between subgroups of the total group and each nation based on the demographic profiles and injury related characteristics.

Objective 3: To carry out a survey in order to report on the quality and intensity of LBP for the total group and each national group. In addition, to examine for differences and similarities between subgroups based on the demographic profiles and injury related characteristics.

Objective 4: To report on the QoL for the total group and each national group. In addition, to examine the differences and similarities between subgroups based on the demographic profiles and injury-related characteristics.

Objective 5: To report on the function for the total group and each national group. In addition, to examine the differences and similarities between subgroups based on the demographic profiles and injury-related characteristics.

Objective 6: To examine the relation and possible impact of the presence of LBP, MSKP and pain on QoL and function for the total group and for each national group.

Objective 7: To examine how the quality and intensity of LBP relate to QoL and function for the total group and for each national group.

The first objective is answered by examination of the literature and the remainder by conducting a survey study. In total, 13 hypotheses were created at the onset of the study which will be analysed in Chapters 6 to 9. These hypotheses have been grouped into three "hypotheses themes", each theme focusing on factors related to the pain experience. The first theme investigates the presence of pain, MSKP and LBP. The second theme investigates the impact of the onset of pain and LBP post iSCI. Finally, the third theme investigates the relationships between LBP quality or intensity and other variables of interest. To assist reading, when referring to all types of pain (i.e. pain in general, MSKP and LBP) they will be referred to as "pain categories". All the hypotheses were examined for the whole group and across each national group.

In particular, the first hypothesis theme includes the following three hypotheses:

Table 1.1: First hypotheses theme

Hypotheses about presence of pain, MSKP and LBP
H 1: In people with iSCI there is a significant difference in the percentage of those with LBP and those without.
H 2: In people with iSCI there is a significant difference in QoL between those with pain, MSKP or LBP and those without.
H 3: In people with iSCI there is a significant difference in function between those with pain, MSKP or LBP and those without.

Abbreviations: MSKP, Musculoskeletal pain; LBP, Low Back Pain; iSCI, Incomplete Spinal Cord Injury

The hypotheses falling into the second theme are:

Table 1.2: Second hypotheses theme

Hypotheses about the impact of pain and LBP onset post iSCI
H 4: In people with iSCI there is a significant correlation between pain onset post iSCI and the number of pain or LBP days felt in a month.
H 5 In people with iSCI there is a significant correlation between the number of areas with pain and the onset of pain or LBP post iSCI.
H 6: In people with iSCI there is a significant correlation between QoL and the onset of pain or LBP post iSCI.
H 7: In people with iSCI there is a significant correlation between function and the onset of pain or LBP post iSCI.

Abbreviations: LBP, Low Back Pain; iSCI, Incomplete Spinal Cord Injury

Finally, the hypotheses under the third theme are:

Table 1.3: Third hypotheses theme

Hypotheses in relation to LBP quality and intensity
H 8: In people with iSCI there is a significant correlation between quality of LBP and pain or LBP onset post iSCI.
H 9: In people with iSCI there is a significant correlation between intensity of LBP and pain or LBP onset post iSCI.
H 10: In people with iSCI there is a significant correlation between QoL and quality of LBP.
H 11: In people with iSCI there is a significant correlation between QoL and intensity of LBP.
H 12: In people with iSCI there is a significant correlation between function and quality of LBP.
H 13: In people with iSCI there is a significant correlation between function and intensity of LBP.

Abbreviations: LBP, Low Back Pain; iSCI, Incomplete Spinal Cord Injury

1.4 Statement of significance

This study makes a significant contribution to the literature by producing a systematic literature review on chronic MSKP (CMSKP) and chronic LBP (CLBP), the first to be conducted in SCI, to this author's knowledge. This could be used as a point of reference for people interested in the topic.

A second significant contribution is the detailed examination of LBP in iSCI and its relation to QoL and function as reported by the respondents. This is important in

helping health professionals to understand better the needs of this patient group and direct research, assessment and treatment appropriately.

One more novel contribution of this study is the translation into Greek of a functional independence measure, Spinal Cord Independence Measure v3 (SCIM III), for the first time. A preliminary validation is also conducted. In addition, for the first time this tool is used as a self-reported measure for both the English and the Greek versions. It is expected that researchers and therapists will benefit from these new ways to use SCIM III.

A final original contribution is that for the first time QoL and function of people with iSCI from Greece are assessed. The findings of this part of the study will assist health professionals in Greece both in clinical and research settings which they can develop further.

1.5 Route to thesis chapters

This thesis is structured in the following way:

Chapter 1

The current chapter has offered an introduction to the background of this research and discussed the basis of this project in a general framework. The three thematic areas of the study have been presented along with their hypotheses. The significant contributions of the study have been summarised and these will be explored in detail in the chapters to follow.

Chapter 2

This chapter will review the literature related to the three major areas of interest. It will include an examination of understanding the experience of pain and will seek to present the current literature on how pain relates to QoL and function. The aim will be to describe in detail the current knowledge on the related topic and identify any gaps that need to be addressed.

Chapter 3

Chapter 3 is a systematic literature review on CLBP and CMSKP in SCI. The approach and the results of this systematic review are presented step by step. LBP is the main category of pain examined in this project and a systematic literature review became essential and informative.

Chapter 4

Chapter 4 will explore the methodology required to translate into Greek the questionnaire used in the study. In the absence of specific guidelines when translating a standardised, validated tool into another language, it is argued that a combination of the best techniques used in other guidelines is appropriate. This approach has been followed and the suitability of the procedure and the methods used will be presented.

Chapter 5

Chapter 5 will describe the methods used to collect data for the current survey. The decisions to use these methods and their appropriateness will be explained. This chapter will discuss the statistical methods used for data analysis and explain their advantages and disadvantages.

Chapters 6 – 9

Chapters 6 to 9 will present the results of the statistical analysis performed. The first three chapters (6, 7, 8) will use the pooled data of all the respondents. Chapter six will present the profiles of the respondents and will answer the core question of the study.

Chapter 7 will start by describing the overall reported QoL of the respondents and will then examine how this may differ based on the participants' demographic profiles. Most importantly, an investigation of how the experience of the pain categories may relate to QoL will be carried out.

Chapter 8 will set out the analysis related to the functional independence of the participants. Initially, the tests to validate the function measure translated and used in Greek will be presented, a procedure essential to ensure appropriate usage of the tool. Then this chapter will exhibit the analysis conducted in regard to function. The Greek group will be examined separately from the rest of the group for reasons that will be

explained in full. Chapter 8 will also examine the possible effect(s) of the experience of pain on function.

Finally, chapter 9 will present the cross-national analysis focusing on answering the hypotheses examined in chapters 6, 7 and 8 using between and within national group analysis.

Chapter 10

Chapter 10 will discuss the findings of the study reflecting upon the aim, objectives and hypotheses. It will investigate current findings in relation to similar or dissimilar findings in the literature and it will seek to explain them.

Chapter 11

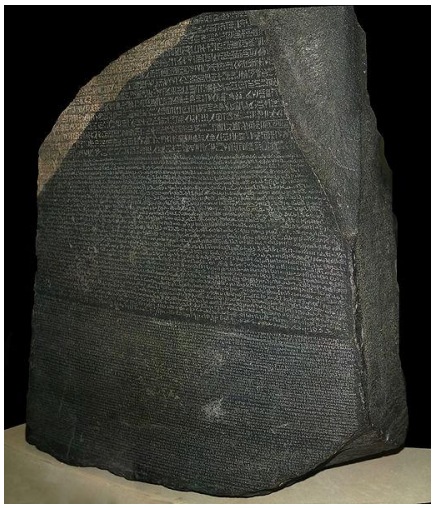
Chapter 11 will discuss the contributions of the project to the field of knowledge in SCI, in terms of importance for health professionals and patients. This chapter will critically appraise both the strengths and the limitations of the project and will propose future studies.

1.6 General note on thesis presentation

Footnotes exist throughout the thesis. They are numbered using the arithmetic system and they are referred in the text with a subscript number (e.g. $_1$). When a subscript number occurs, please see the relevant footnote for explanation. References are in an adapted Vancouver system, which is widely used for health-related documents in various peer-reviewed journals, and uses an arithmetic system which is referred in the text with a superscript number (e.g. ^{1}). When a superscript number occurs, please refer to the reference list, which will be in alphabetic order. In data analysis the Bonferroni correction has been used which, as it will be explained in Chapter 5, reduces the alpha level of significance below $p \leq 0.05$. Each test that passes the Bonferroni correction (or Bonferroni post hoc) will be marked in **bold** colour. Each test that does not pass the Bonferroni correction but is $p \leq 0.05$ will be presented but not marked in bold. Finally, the thesis is followed by appendices which are divided into nine sections and references will be made as appropriate throughout the thesis.

Chapter 2; Literature Review

Chapter Brief Table of Contents



[2]"In literature as in love, we are astonished at what is chosen by others."

Andre Maurois (1885 – 1967) - French biographer, novelist and essayist

[2] Picture of the Rosetta Stone, taken from www.wikipedia.org The Rosetta Stone is attributed to the Ptolemaic Period, Egypt 196 BC. It has three scripts; Ancient Egyptian hieroglyphs, Demotic and Ancient Greek.

Part 1; Spinal Cord Injury and the experience of pain

2.1.1 Introduction

The previous chapter gave an overview of the three areas that will be examined in this study, pain, QoL and function, and presented the aim, objectives and hypotheses. This chapter will explore, in detail, the background information that is available on the topics of interest with the aim of identifying those areas that need further investigation.

The chapter will be divided in two parts; the first will include an overview of cross-national research and the general profiles of the three participating countries. It will then move on to describe SCI and conclude by looking at the experience of pain and what it involves. The second part will review both QoL and function examining what can influence them and what is known about them in people with SCI.

2.1.2 Health and disability

The World Health Organisation (WHO) defined health as "*a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity*".[499] Disability is part of the human condition, it is complex, and almost everyone will be temporarily or permanently impaired at some point in their lives.[499] The estimated prevalence of disability worldwide is 15% with 2.2% to 3.8% of the world's population having severe disability.[499] The number of people with disability is growing due to a number of factors including the ageing population and the global increase in chronic health conditions associated with disability.[499]

People with disabilities have poorer health compared to the general population, depending on the type of disability and the setting they live in, they may be more vulnerable to secondary complications or co-morbidities, and they may be at higher risk due to poor diet and reduced physical activity.[499] People with disabilities tend to

have reduced educational achievements as well as a reduction in their economic participation, as they have reduced employment rates and earn less money when employed.[499] Consequently, higher rates of poverty are reported compared to non-disabled people.[499] In this study, emphasis will be given to one particular type of disability, SCI.

2.1.3 Cross-national research

Ross and Homer[388] gave a brief summary of the history of cross-national research and what was known as "Galton's problem in cross-national research". They quoted a study published in 1889 by Edward Tylor on the relationship between marriage and descent patterns. That study used data from a cross-cultural sample which led to a critique paper by Sir Francis Galton who said that the correlation found by Tylor could have been due to contact between cultures and questioned if the cases were really independent.[388] "Galton's problem" and criticism resulted in researchers hesitating to conduct cross-cultural studies for the next 50 years.[388] More recently, theories and "solutions" to Galton's problem have begun to emerge.[388]

A broad definition of cross-national research is "*any research that transcends national boundaries. It is an explicitly comparative study that utilizes systematically comparative data from two or more nations*".[245] According to Kohn,[245] cross-national research is a type of comparative research that is more complex than other types of comparative research but benefits from being able to carry out a broader range of comparisons, thus not limiting comparisons to a single nation. It is a valuable type of research which enables generalisation of findings, validating interpretations from single-nation studies, forces revisions of interpretations by taking into account cross-national differences that cannot be revealed via single-nation studies and raises questions about the generalisations made in single-nation studies.[245]

Cross-national, cross-cultural or international research has increased rapidly over the last few decades possibly because of globalisation and the easiness of transportation between countries which, on the one hand, enables, but on the other hand requires

these types of research. Most recently more advanced technological developments and, in particular, the internet can facilitate completion of cross-national studies. Internet research will be discussed in detail in Chapter 5.

Kohn[245] referred to four types of explicit comparative cross-national research:

1) Where a nation is the object of study; the interest is primarily on the countries studied and understanding of each country;[245]

2) Where a nation is the context of a study; interest here is primarily on the generality of the findings and the interpretation of how social institutions and social structures can affect the people of a given nation;[245]

3) Where a nation is a unit of analysis; in this case the country is not classified by name but from other socio-economic factors like national income, educational level etc. and the interest is in establishing relationships among the characteristics of nations;[245]

4) Those which are transnational in character; in this case the country is part of a larger international system.[245]

Kohn[245] pointed out the difficulties often faced with differentiating between a study that uses a nation as object or as context, and also said that the differences between research that uses a nation as a unit and not as context are not sharp either.[245]

There are two research strategies employed in cross-national studies; looking at similarities and differences.[245] Finding similarities across nations are easier to interpret sociologically and their explanation should be focused on identifying the structural similarities between the countries.[245] Finding differences among the examined nations is more difficult to interpret and the explanation may be due to historical, cultural, political or economic reasons.[245]

The number of countries to be included in a cross-national research project should be small with the aim of conducting some systematic, intensive study.[245] Cross-national research can be costly and requires the establishment of good collaborations. Thus the

reason for embarking on it should be either because the topic studied cannot be studied unless following this methodology or because it has been studied enough in one country and the next logical step is to study it in another, thus discussing generality.[245] Pain in general and/or QoL in SCI have been studied mainly in single-nation studies[116,251,260,313,368,481] and, more recently, in some international studies.[255,294] Function has been investigated via single-nation studies[252,353,331] and international studies[65,222,266,495] in SCI. Often the studies that examined QoL subsequently looked into function because many QoL measures include items on function. However, at the time of designing this study the author was not aware of a cross-national study on SCI to investigate QoL and function together (using different assessment tools) and examine them in relation to pain. In addition, research on SCI in Greece is limited, thus, designing a cross-national research study was a promising research approach.

Kuechler[256] described some principles which aim to reduce validity problems encountered in cross-national research. The first is that people from the different countries should have similar experiences and exposure to surveys and, more general, the nations should not to be too distant with regard to their development and politico-economic systems.[256] Of course, the latter principle is not valid where the aim is to compare the different politico-economic systems between countries.[256] The three countries participating in this study are similar in their politico-economic structures as it will be described in the following section. Validity problems with cross-national research can be minimised by applying similar sampling selection methodology for each country but some variation could exist if the needs or the possibilities for recruiting vary within the nations.[256] Such a variation in the recruiting methodology for the current project was necessary and this will be explained in Chapter 5.

One of the main problems in comparative research is “equivalence” which means identifying equivalent phenomena and analysing the relationships in an equivalent way.[365] Equivalence, on the one hand, may not be a necessary concept in some countries but, on the other hand, it can be influenced by external phenomena which may be common to all countries but not equally relevant to them.[365] Przeworski & Teune[365] pointed out that complete equivalence is unlikely to happen but researchers

may attempt to measure equivalence. One way to do this is by examining homogeneity; i.e. if some indicators correlate in a within-nation analysis and they maintain their correlation in a pooled, cross-country analysis then this gives validity to the concept.[365] Another way to examine equivalence is by analysing data relationships separately within each country and then compare across countries.[365] In order to be able to confirm a hypothesis cross-nationally, the within-country relationships must not differ.[365] The strength of the relationship may differ from country to country which may help identify which other variables could influence each country individually.[365] This study follows the second way to examine equivalence.

2.1.4 General profile of countries

As mentioned above, the general development and politico-economic profiles of the countries participating in a cross-national study should be similar[256] and the number of participating countries should be small.[245] Of course, politico-economic and developmental changes have occurred rapidly around the world over the last few years, affecting all three participating countries, a general profile of which is presented in brief below. The information that will be used to describe the countries will be based mainly on data related as closely as possible to the period of collecting data for this study (2008-2009).

2.1.4.1 United States of America

The USA has a democratic political system, has a population of around 310 million people, 50.8% of whom are females, with a life expectancy of 79.6 years.[338] It is located in North America covering an area of 9.83million Km² and consists of 50 states and 1 district area.[70] Its capital is Washington DC with a population of 4.4million people and migration is 4.18 migrants/1000 people.[70]

Overall, it has maintained a stable ranking of fourth place on the Human Development Index[3] over the years 2005-2011.[218] Expected (compulsory) mean schooling years are 15.7, which are the lowest among the three countries examined but attended mean schooling years are 12.4, which is the highest among the three countries. The country spent 7.3% of its Gross Domestic Product (GDP) on public expenditure on health (in 2007) and 15.9% on public social expenditure (in 2005).[335] Among the three countries the USA spends the most on public health but the least on social expenditure. The country spent 2.66% of its GDP on research and development (R&D) in 2007 which is the highest among the three countries.[335] In 2005, the disability percentage was 18.7% (including all types of disabilities) and it was higher among females (20.1%) compared to males (17.3%). Fewer than half (46%) of people with disabilities aged 21-64 were employed.[37] Among 10.2 million accidents there were 37,261 fatalities and 2,346,000 injuries in 2008.[338]

2.1.4.2 United Kingdom

The UK has a population of 62.3 million people and a life expectancy of 79.8 years.[456] The UK consists of England, Wales, Scotland and Northern Ireland and comprises an area of 244,820km² and its capital is London.[136] It has a constitutional monarchy and a parliamentary democracy and has been a member of the European Union (EU) since 1973.[136] The UK is the home of the industrial revolution and has produced many great scientists. It is also home to diverse immigrant communities that mainly come from its former colonies.[136]

The UK is another very highly developed country which ranks from 22nd to 28th positions over the years 2005-2011 on the Human Development index.[218] Expected

[3] The Human Development Index is an annual world report that examines the dimensions of health, education and income for each country. It refers to their economic growth but also includes many other related aspects like social progress, efficiency (including resource use and availability), equity, participation and freedom, sustainability (ecological, economic and social), human security, education, perception of individual's well-being and health. The first 47 counties are labelled as having "very high human development".[218]

mean schooling years are 15.9, but attended mean years are 9.5, the lowest among the three countries (in 2010). Public expenditure on health was 6.9% of GDP (in 2007) and 21.3% on public social expenditure (in 2005).[336] The country spent 1.82% of its GDP on R&D in 2007.[336] The prevalence of disability in the UK is around 18% and people with a disability are twice as likely not to have a qualification and their employment rate is around 48%.[208] In 2010, in Great Britain alone there were 1,850 people killed in road traffic accidents (RTAs) (including pedestrians), 22,660 seriously injured and 184,138 slightly injured.[105]

2.1.4.3 Greece

Greece is the smallest of the three countries participating in this study; it has a population of around 11 million people, 50.8% of the population are females and life expectancy is 79.7 years.[199] Greece forms a crossroad between Europe and Asia, located at the South-East end of the Balkan Peninsula. It covers a total area of 131,957km² including more than 2000 islands.[137] Its capital is Athens which has a population of nearly 4 million.[199] The country consists of 13 regions, is a member of the EU since 1981 and is a member of the Eurozone.[137] Greece is one of the most ancient civilisations with scholars who have contributed greatly to mathematics, philosophy, astronomy, politics and medicine. In the ancient world Greece consisted of city-states which pioneered the democratic system. Today, Greece is a republic with its current constitution since 1975.[137]

Similar to the UK and USA, Greece ranks among the very highly developed countries of the world, ranking from 22nd to 29th positions during the years 2005-2011 on the Human Development index.[218] Expected mean years of schooling are 16.5 which is the highest among the three countries, and attended mean years are 10.5. The country spent 5.8% of its GDP on public health expenditure (in 2007), which is the lowest among the three countries, and 20.5% on public social expenditure.[337] The country spent the least among all three on R&D, 0.58% of its GDP in 2007.[337] The prevalence of people with disabilities (all types) is 18.2%,[482] which is very similar to that reported in

the USA and UK. In around 18,000 annual RTAs (including accidents to pedestrians) there were about 1,500 fatalities, 1,500 severely injured and 17,000 slightly injured (in 2007),[482] which is a large number for the size of the population.

Summary

In summary, all three countries are among the 30 most highly developed countries in the world and have maintained their positions with no great changes over the last six years. Among the three countries, the USA ranks highest, spends the most money on public health and the least on public social expenditure. Greece spent the least money on public health though the differences are not great. The disability rate is very similar across the countries. Finally, the USA invests a lot more on R&D than the other two countries, particularly Greece. This may reflect the reason why in the literature, as will be discovered in the sections to follow, the vast majority of the studies on SCI are conducted in the USA. This may also imply that people within these three countries have different exposure to participating in research and more than one method of recruiting participants may be essential as will be explained in Chapter 5. Despite some differences, the selected countries have similar politico-economic profiles thus their selection for this study is not expected to bias results due to major differences in their general profiles.

2.1.5 Spinal Cord Injury; a brief historic overview

Spinal Cord Injury is "*an insult to the spinal cord resulting in a change, either temporary or permanent, in its normal motor, sensory, or autonomic function*".[95]

Reports on SCI, its symptoms, including pain, and early treatment have been found in ancient Egyptian papyrus, in Homer's Iliad and spinal stabilisation techniques were described by Hippocrates (ca.460-ca.370 BC).[173] The Egyptian papyrus, dating from 3000 to 2500 BC describes an incomplete cervical SCI as "an ailment not to be treated (cured)".[134] In ancient Greece, Hippocrates described paraplegia and used traction methods for the treatment of SCI.[134] In his book "Anatomy of the spine" he described

mechanisms in SCI that may be fatal (related to fall injuries) and he used the same treatment methods (like the extension bench) for both traumatic and non-traumatic SCI.[134] Galen (131-201 AD), in ancient Rome, followed the Hippocratic methods and described, in more detail, the spinal cord anatomy.[134] In the middle ages (700-1400 AD) the treatment of SCI developed to include diet and hygiene.[134] During the Renaissance period, the Hippocratic techniques were modified by various physicians. At that time, there was a gradual transition from the Greek and Latin languages to French and English and thus medicine started developing in Western Europe.[134] In the 17th and 18th centuries, anatomy dissection was allowed in Europe.[134] In the 19th century, further descriptions of SCI lesions, like cauda equine and Brown-Sequard Syndrome, were made. Advances in treatment and rehabilitation also occurred, like the plastic jacket for postsurgical stabilisation by Burrell in 1887.[134] Famous people, like Admiral Lord Nelson (battle of Trafalgar 1805), and James Garfield (President of USA 1881), sustained SCIs and died.[124]

Death is the most serious consequence of SCI. At the beginning of the previous century mortality due to SCI was high reaching 65%.[52] Death after SCI frequently occurred within one month, and up to 78% of people injured could die in the first five days.[52] Major advances in surgery and rehabilitation in SCI happened in the second half of the 20th century.[134] In 1944, Guttmann created a unit at Stoke Mandeville in UK, where a multidisciplinary approach to the rehabilitation of SCI was followed.[134] In time, more SCI centres started opening around the modern world.[134]

Nowadays, life expectancy after SCI, if injured at the age of 20, can vary from 33 to 44 years.[95] The survival rate of people with SCI has increased to as high as 85%.[114] If injured at younger age than 25 years and sustaining an incomplete injury, individuals can have a survival rate as high as 95%.[114] People with injuries at C1-C3 level can have more than six times higher mortality rate.[114] Life expectancy still remains poor if injury occurs at the age of 50 years and above.[114] Another factor, apart from age, determining life expectancy is severity of injury.[53] Previously, the main causes of death were renal diseases but recently respiratory complications have become the leading cause.[53] As life expectancy after SCI is on the increase, non-SCI related causes of death,

like cancer, are on the increase too.[53] More recently, Strauss et al[425] concluded that in the last 30 years the critical care provided in the first two years post injury has greatly progressed and survival rates and life expectancy have increased considerably. But the difference between the life expectancy for people who have survived the first two years of their SCI and the general population still remains increased.[425]

2.1.6 Spinal Cord Injury; epidemiology

2.1.6.1 Spinal Cord Injury; Incidence and prevalence

Over the last 30 years the prevalence and incidence of SCI have not changed a lot but there is still a lack of registration of SCI cases.[503] A review study aiming to estimate an international incidence and prevalence of SCI concluded that the incidence of SCI is between 10.4 and 83 per million inhabitants annually.[503] The data however, came mainly from North America, Europe and Australia which, according to the authors, made up only 20% of the world's population in 1999. In addition, in the vast majority of countries, people who died at the scene due to a SCI were not counted in the incidence total.[503]

In the USA the estimated SCI cases that required hospital admission has been reported to range from 32-50 cases per million people.[231,433] It is estimated that in the UK there are 900-1000 new SCI cases per year and about 40,000 people live with SCI.[482] There are not many publications that have investigated incidence or prevalence of SCI in Greece, but recently some have examined regional epidemiology. Examining the incidence of traumatic SCI in the region of North Greece, Divanoglou et al[122] found it to be 33.6 per million population per year (including people who survived one week post injury). In another study conducted on a Greek island, 38 cases were reported among a population of about 54,000 inhabitants.[249] Prevalence has been more difficult to estimate as very few reports exist in the literature; an estimated figure is 223-755 per million inhabitants. However available data is insufficient.[503]

2.1.6.2 Spinal Cord Injury; Gender

More men than women sustain SCIs and the ratio is 4:1, but the difference between the two sexes is reducing[332] and a ratio of 3:1 has been reported.[490] In one Greek study, a 7:1 ratio was reported and the authors attributed this finding to cultural reasons.[122]

2.1.6.3 Spinal Cord Injury; Age

SCI occurs most frequently in young men followed by people aged between 55-74 years.[53] The average age at injury has risen over the past few years, but still 50% of people who sustain SCI are aged 16-30.[332] Recent studies on Greek SCI groups reported a higher mean age at injury (above 40 years),[122,249] but in the past a lower mean age at injury was reported.[392]

2.1.6.4 Spinal Cord Injury; Causes

The primary cause of SCI is road traffic accidents, followed by falls and then sports accidents.[53] As the ageing population is increasing, it is believed that injuries related with spondylosis and caused by falls will increase.[53] Some of the causes of SCI can be explained culturally and economically, for example, in economically developing countries road traffic accidents are more common while in other countries violent injuries are more frequent.[53,122] Gender can also explain some of the causes of SCI as intentional violence is more common among men[53] and the incidence of violence-related SCI has been rising.[332]

2.1.6.5 Spinal Cord Injury; Types and levels

Injury occurs most frequently at the lower cervical and thoracolumbar regions and fractures at more than one level of the spine can occur.[53] The different types of SCI are defined by the American Spinal Injury Association (ASIA) as follows:

Tetraplegia is caused by "*the impairment or loss of the motor and/or sensory function in the cervical segments of the spinal cord due to damage of the neural elements within the spinal canal*".[9]

Tetraplegia involves the loss of muscle strength in all extremities[95] including the trunk and the pelvis but excluding brachial plexus lesions or injury to peripheral nerves.[9]

Paraplegia is caused by "*the impairment or loss of motor and/or sensory function in the thoracic, lumbar or sacral (but not cervical) segments of the spinal cord, secondary to damage of neural elements within the spinal canal*".[9]

In paraplegia the arms maintain their function but depending on the level of the injury the trunk, legs and pelvis can be affected. Paraplegia may involve injury to the cauda equine and conus medullaris but not the lumbosacral plexus or injury to the peripheral nerves.[9]

Complete SCI results in "*loss of sensory and motor function below the level of lesion and the severity of the symptoms depend on the level of injury*".[482]

Incomplete Spinal Cord Injury (iSCI) is "*the partial preservation of the sensory and/or motor function below the neurological level and includes the lowest neurological sacral segments*".[9]

If there is an iSCI at the onset of injury then some improvement may occur and recovery can go on for at least two years, however much of this improvement depends on the severity of the condition.[53]

Using the ASIA Impairment Scale (AIS), SCI is further classified as shown in Table 2.1.1.

Table 2.1.1: ASIA classification of SCI[9]

A	Complete	No sensory or motor function is preserved in the sacral segments S4-S5.
B	Incomplete Sensory	Sensory but not motor function is preserved below the neurological level and includes the sacral segments S4-S5.
C	Incomplete Sensory & Motor	Motor function is preserved below the neurological level, and more than half of the key muscles below the neurological level have a muscle grade less than 3.
D	Incomplete Sensory & Motor	Motor function is preserved below the neurological level and at least half of key muscles below the neurological level have a muscle grade greater than or equal to 3.
E	Normal	Sensory and motor function are normal

Abbreviations: ASIA, American Spinal Injury Association; SCI, Spinal Cord Injury

2.1.6.6 Spinal Cord Injury; Clinical Syndromes

According to ASIA[9], iSCI includes a number of clinical syndromes.

Central Cord Syndrome is "*a lesion occurring almost exclusively in the cervical region that produces sacral sensory sparing and greater weakness in the upper limbs than in the lower*".[9]

Brown-Séquard Syndrome is "*a lesion that produces relatively greater ipsilateral proprioceptive and motor loss and contralateral loss of sensitivity to pain and temperature*".[9]

Anterior Cord Syndrome is "*a lesion that produces variable loss of motor function and of sensibility to pain and temperature, while preserving proprioception*".[9]

Conus Medullaris Syndrome is "*an injury of the conus and lumbar nerve roots within the spinal canal, which usually remains in an areflexic bladder, bowel and lower limbs. Sacral segments may occasionally show preserved reflexes".*[9]

Cauda Equina Syndrome is "*an injury to the lumbosacral nerve roots within the neural canal resulting in areflexic bladder, bowel and lower limbs*".[9]

As seen in the literature presented above, spinal injuries vary widely in level and extent and, as a result, a variation in their consequences is expected. People with SCI will differ in their abilities, limitations or challenges depending on the severity of their injuries. The vast majority of the literature on SCI includes people with all types of injuries, pooling them together in the analysis and frequently no subgroup analysis is reported. Often, other studies focus on recruiting participants based on the cause of their injuries rather than the type. Undoubtedly, these studies have contributed valuable information to the SCI literature, but the current study will examine people based on the type of their injury, as the type of injury determines the level of functionality as per ASIA classification.[9] This study will examine people with incomplete SCI. Looking back at Section 2.1.6.5, a complete injury results in motor and sensory loss below the level of injury[482] which indicates that function but also the sensation (or presence) of pain can be different when compared to people with incomplete injuries. Of course, there is a variation of disability within the incomplete injuries, thus this study will carry out subgroup analysis as well.

2.1.7 Spinal Cord Injury; secondary complications

Secondary complications are common in SCI, more than 95% of people will have one and around 60% will have three or more.[13] These complications are listed and described below:

2.1.7.1 Spinal Cord Injury; secondary complications; neurogenic bladder and bowel

Problems of the bladder due to SCI may require the use of long-term bladder drainage with the aim of avoiding kidney damage and preventing complications like repeated infections and stone formations.[53] Bowel mobility is usually reduced and care, often with the use of laxatives and suppositories, is needed in order to limit the risk of incontinence.[53] People with tetraplegia and people older than 60 years often have more abnormal renal tests, increased number of stones in the kidney and/or ureter, in particular, if they have complete tetraplegia.[296]

2.1.7.2 Spinal Cord Injury; secondary complications; cardiovascular, circulation and pulmonary problems

After SCI there is an increased risk of deep venous thrombosis (DVT) (by 15-20%) and pulmonary embolism (by 5%).[53] The risk is higher for people with complete injuries,[53] particularly during the first year compared to people with incomplete injuries.[296] Pulmonary function is reduced in most cases of SCI even for people with paraplegia and it is affected by increased duration of injury.[267] Atelectasis or pneumonia can affect 3.5% of people during the first year and, overall, people older than 60 years develop pneumonia more often.[296]

People with SCI tend to have lower than normal blood pressure, relative bradycardia, and they can suffer from postural hypotension which may result in symptoms as serious as the loss of consciousness.[53] Autonomic dysreflexia may occur in severe SCI at levels T5 and above and its symptoms can include headache, paraesthesia, chest tightness, dyspnoea, occasionally cardiac arrhythmias or even myocardic failure.[53]

2.1.7.3 Spinal Cord Injury; secondary complications; spasticity

Spasticity is a common consequence of SCI and tolerance to it may vary.[53] It may interfere with transfer abilities, causing falls, but on the other hand it may be beneficial by assisting in achieving transfers.[53]

2.1.7.4 Spinal Cord Injury; secondary complications; pressure ulcer

Pressure ulcers, which are lesions caused by pressure, usually over bony areas and which result in tissue damage, are common in SCI and are a lifelong complication.[161] Pressure ulcers have been noticed and recognised since ancient times; Egyptians applied topical remedies, Arabs used nutrition to promote healing and during the Renaissance good hygiene was proposed.[134] In the last century, the use of antibiotics and surgery were developed.[134] McKinley et al[296] recorded pressure ulcers as the most frequent secondary medical complication present in 15% of people with SCI in the first

year and more people were affected in the following years. People with incomplete lesions are less likely to develop pressure sores or pressure ulcers and males and people with a violent onset of injury report them more often.[296]

2.1.7.5 Spinal Cord Injury; secondary complications; spinal deformities

Spinal and/or pelvic deformities may develop following SCI, affecting the person's ability to maintain a correct sitting position.[102] The following deformities may appear following injury or may pre-exist leading to SCI:

2.1.7.5.1 Scoliosis

There are many different types of scoliosis including idiopathic, congenital, degenerative and neuromuscular.[287] The last two can be due to degeneration of the discs or arthritis of the joints of the spine and due to defects of the neuromuscular system and muscle forces that support the spine.[287]

Scoliosis can follow trauma to the spine that results in tetraplegia or paraplegia,[287] and it can affect up to 15% of people with SCI by the third year of their injury.[230] The degree of the curve does not correlate with the completeness or the level of the SCI[100] but people with paraplegia and complete SCI have greater scoliosis.[23] Interestingly, paralytic scoliotic deformity affects as many as 97% of pre-adolescent SCI patients and 48% of mature SCI patients. The pre-adolescent curve can progress twice as fast as the adolescent curve and, in the majority of the cases, an operation is needed to stop progression.[100] Muscles that are weakened due to an underlying neuromuscular condition in combination with the beginning of the growth of the scoliosis, can result in the worsening of the scoliotic curve[287] which can then become a fixed deformity.[320] The paralysed muscles cannot support the spine leading to loss of sitting balance.[287]

2.1.7.5.2 Kyphosis

Both congenital kyphosis and kyphoscoliosis are less common than scoliosis but are more serious and occasionally lead to spinal cord compression and paraplegia.[297] McMaster and Singh[298] found that 10% of people with kyphosis or kyphoscoliosis

developed a progressive spastic paraparesis of the lower limbs due to anterior compression of the spinal cord at the apex of the deformity.

Around 90% of people with traumatic paraplegia were found to have developed a post-traumatic kyphosis of up to 65°.[2] In wheelchair users with SCI kyphosis can extend to the lumbar spine.[23]

2.1.7.5.3 Lordosis

The causes of lordosis are unknown but it could be associated with poor posture, congenital problems of the vertebrae, neuromuscular problems, and back surgery or hip problems.[334] People with SCI have been reported to have bigger lumbar angles compared to healthy controls[209] and lordosis is reported to be greater in people with paraplegia and incomplete lesions.[23]

2.1.7.5.4 Pelvic tilt and obliquity

People with SCI have a more passive sitting position with a backward pelvic tilt, and their back leaning against the backrest for support.[363] They may develop a c-shaped posture in an effort to compensate for their loss of balance.[30] Patients with SCI were found to have posteriorly rotated pelvises[401] and reduced pelvic angle by as much as 15° compared to healthy people and pelvic obliquity of about 1.5°.[209]

In the neuromuscular disorders the pelvic tilt is one part of a composite deformity, which includes the hip joints and the spine. The patient sits with uneven weight bearing which makes sitting painful and this sitting position creates an unstable base for the spine.[287] Four different types of pelvic tilt in combination with spinal and hip deformities have been reported and one of them can be found in people with tetraplegia; type III (wind-blow-hip syndrome) in which there is scoliosis and pelvic tilt together with unilateral hip dislocation.[159] People with SCI have been found to have pelvic deformities,[401] pelvic tilt being greater in people with paraplegia and pelvic obliquity being present in as many as around 70% of the SCI population studied.[23]

The treatment of neuromuscular spinal disorders follows the same philosophy as in non-neurological conditions. The aims are to improve balance and stop curve

progression,[320] to prevent pain or offer pain relief,[234,287] but even though surgical correction can greatly correct the deformity, it cannot always completely stop the pain.[479]

2.1.7.6 Spinal Cord Injury; secondary complications; ageing with SCI

As life expectancy following SCI has been increasing over the last century, the consequences of living with SCI and the associated problems with ageing eventually become more apparent, and include other symptoms like increased shoulder and upper limb pain, added urinary management, constipation, an increase in pressure ulcers, fatigue, increased pain and spasticity.[53] In addition, psychological consequences, for example, feelings of isolation may present, and all the above may lead to the loss of independence.[53]

2.1.7.7 Spinal Cord Injury; secondary complications; pain

Another secondary complication, following SCI, is pain. Both acute and chronic pain have been extensively studied in SCI. Pain is the focus of the current research therefore it will be discussed in detail later in this thesis.

2.1.7.8 Spinal Cord Injury; secondary complications; other

Fractures of the long bones of the lower extremities is another secondary complication post SCI, though not often seen but more common in people over 60 years and in women especially, as time post injury increases.[296]

In summary, many secondary complications may follow SCI some of which are common in the general population like cardiovascular problems. The severity of the secondary complications can depend on the severity of the injury itself, but also SCI complications tend to become worse with age. Increasingly, the literature has been investigating these secondary complications, and this project will focus on one of them. Before going further, the experience of pain will be explored.

2.1.8 Understanding pain and the experience of pain

2.1.8.1 A historic route to the definition of pain

2.1.8.1.1 Pain in Ancient Greece

Pain is experienced by all people and has been studied for centuries. Its description goes back to antiquity, for example, there are references to pain in Homer's texts, in the 8th century BC.[378] Various books from Ancient Greece include references to pain, often using words like "exhausting", "sharp", "consuming" or "shooting" to describe it. In addition, there were words like "kedos" (κῆδος) or "achos" (ἄχος) which describe emotions and feelings.[378] In the 5th century BC, Hippocrates (ca 460 BC –ca. 370 BC) discussed pain in more detail, talked about the believed causes and treatment of the time.

Hippocrates said "*Pain arises from cold and from heat, and both from excessively great amounts and from too little. In persons that are cooled by nature out of their body towards their skin, pain arises from excessive heating, in those by nature hot, from cold, in those by nature dry, when they are moistened, and in those by nature moist, when they are dried.* ***From each thing that is altered with suspect to its nature, and destroyed, pains arise.*** *Pains are cured by opposites, and there is a specific thing for each disease: in persons by nature hot, and who are ill because of cooling, it is what heats, and so on according to this principle*".[207]

Hippocrates's ideas were spread to the Greek cities, then via Alexander the Great's conquests to much of the rest of the known world and later the study of pain continued to expand via the Egyptians and the Romans.[378] Herophilus, in Alexandria (3rd century BC), who experimented on live criminals (his work was then stopped on ethical grounds), described seven pairs of cranial nerves and identified the origins of the motor nerves in both the brain and the spinal cord.[378] Erasistratus, during the same period, talked about two kinds of nerves; the sensory and the motor.[378]

2.1.8.1.2 Pain in the Roman period

Another landmark in the study of pain was the Roman period, during the 1st century AD, when Aretaeus of Cappadocia talked about acute and chronic conditions like migraine pain.[378] Galen, during the 2nd century AD, studied and combined medicine, philosophy, anatomy and physiology from the ancient years to his time and wrote many books. He developed his work on pain advancing the ancient theories about the nerves and senses. He focused on the analysis of the mechanism of pain and he set down the basis for its perception. He identified three conditions necessary for the perception of pain; an organ to receive the stimulus, a connecting pathway, and a centre which would organise and transform the sensation into a perception. He attributed pain to the tactile sense.[378] The theories of Galen were followed for many centuries but little progress was made during the middle ages.[378] During the Renaissance years (14th – 17th Centuries), art and poetry described illnesses like the plague and the experience of pain due to famine. Christianity also affected beliefs about pain at this time.[378] New work on anatomy started in the 15th Century AD, with text now been written in Latin and French by doctors like Vesalius and Paré.[378]

2.1.8.1.3 Pain in the Classical Age

The study of pain progressed during the Classical age. Descartes discussed the theory of sensation. He believed that pain was a mode of action, rather than a sensation, involving the nerve of touch. He did not believe pain was caused by opposites. Based on Harvey's discovery of blood circulation, Descartes talked about the transmission of sensation.[378] Willis discussed pain and reflex movements and he described involuntary actions as sensations which warn the organism of danger and produce automatic protective movements.[378] In the so-called "Age of Enlightenment", the 18th Century, physicians started thinking more spherically around the value and the usefulness of pain. They advised that attention should always be paid to reports of pain and tried to classify pain, using ancient knowledge, but in a more organised way. Dr. Renauldin used a four-category classification system and more systems were developed by other pioneers.[378]

2.1.8.1.4 Pain in the 19th Century

The location of pain was studied in the 19th Century and research focused on tissue damage rather than the organ as the source of pain. Knowing how to evaluate pain, by questioning the patient became more important during the 19th Century. The difficulty faced was how to value patients' complaints about their own pain.[378] The concept of sensibility was studied further and the concept of the pain threshold developed.[378] During the 19th Century morphine was discovered, followed by great developments in anaesthesia.[378] During that period further significant developments were made in the study of the nervous system. For example, an understanding of the ascending and descending pathways and of the nerve fibres,[378] as well as the work of Brown-Séquard on the cross transmission taking place in the cord and the establishment of "pain points".[378] War was a constant feature that resulted in many people being injured due to trauma. There was uncertainty expressed as to whether the pain was "real" due to the trauma or due to the psychological effects of war.[378]

2.1.8.1.5 Pain and current theories

Clearly, over the centuries, pain, its causes, its origin, its transmission and its expression has generated debates as all of the above theories had both supporters and detractors. Overall, the tendency was that there had to be a somatic reason which would activate the pain receptors in the periphery and the fibres would then transmit the messages up the spine to the brain in a pain centre. This was the theory of specificity developed by Descartes, three centuries earlier, which was challenged by the "pattern theory" which included a number of forms.[306] Still, the pattern theory explained the role of the brain as a passive one.[306] If there was pain without a physical cause this was attributed to a psychological illness. The debate on pain did not stop.

2.1.8.1.6 The Gate Control Theory

Melzack and Wall developed the Gate Control Theory of pain in 1965,[310] which gave rise to a different approach to understanding pain. They said that the spinal cord is constantly bombarded with incoming impulses, even when there is no obvious stimulation, but small fibres are activated and they do not produce any pain.[310] When

a stimulus is applied to the skin then larger fibres are activated that send messages to the brain. There exists a "central control trigger" which selects and activates particular processes in the brain that has control over the sensory input. According to their model, psychological factors, like previous experience, emotional influences, perception and so on, act on the gate control system.[310] So, the gate control theory of pain gave more emphasis to the function of the brain in the processing of pain. Both Melzack[306] and Wall[476] had reported how astonished they were by the huge support or opposition with which their theory was received. In the light of new research, in 1978, Wall[476] published a summary paper in which he stated that the function of the large fibres in their original gate control theory was over-estimated. Nevertheless, the gate control theory of pain was a landmark in understanding pain better, the mechanism of which is still largely unexplained.[306] Melzack, meanwhile, studying types of pain, like phantom limb pain was realising that the gate control theory could not explain certain types of pain, including chronic pain, thus there must be greater participation by the brain in the production of pain.[306,308,309] Melzack[306] quoted the work of Loeser, of 1978, who studied people with paraplegia and pain in their paralysed areas and developed further on the gate control theory to propose a central "pattern generating mechanism" which existed in the brain.

2.1.8.1.7 The theory of Neuromatrix

Following further work, Melzack then proposed the theory of neuromatrix in 1996.[306] According to this theory, there is a widespread network of neurons in the brain with many loops that include many parts of the brain. The loops constantly perform cyclical processing and synthesis of nerve impulses. All inputs of the body go into the processing of the neuromatrix and some parts of the neuromatrix are specialised into processing information related to sensory events such as an injury.[306,308,309] The neurosignature is a continuous outflow from the body-self neuromatrix, and is converted into awareness. It can also activate the appropriate networks to create movement.[306,308,309] Melzack,[306,308,309] concluded that chronic pain could be the cumulative effect of cortisol, which is released in injuries, on the muscles, bones and neural tissue. But he added that cortisol on its own is not sufficient to cause chronic

pain, but it is a contributing factor along with sex-related hormones, genetic predisposing factors and psychological stresses. In conclusion, the neuromatrix theory of pain is produced by genetic and sensory influences and by stressors of a physical or psychological nature that could explain chronic pain.[306,308,309]

Summary of history of pain

Thus, the latest theory of pain, mainly attributable to the work of Prof. Melzack, is that pain is a multidimensional experience produced by multiple influences in the brain neuromatrix which creates sensory, affective and cognitive dimensions of the experience of pain and the behaviour that accompanies it.[308]

The historic route to the definition of pain has changed massively over the course of the centuries from Hippocrates' theory of the opposites, to the current definition of "*an unpleasant **sensory and emotional experience** associated with **actual or potential** tissue damage, or described in terms of such damage*".[220]

2.1.8.2 Chronicity of pain and pain classification in Spinal Cord Injury

In 2008 the International Spinal Cord Injury Pain Basic Data Set (ISCIPDS:B) was published as the result of the collaboration of four major organisations with an interest in SCI (ASIA, American Pain Society, International Spinal Cord Injury Society and International Association of the study of PAIN (IASP)).[483] The aim of the basic data set is to facilitate collection and reporting of pain in people with SCI, assisting comparisons across the world.[483] Prior to this collaborative work many pain classification systems had been reported in other studies but ISCIPDS:B proposed seven types of pain that include many previously described categories.[483]

Table 2.1.2: Pain classification in SCI according to the International Spinal Cord Injury Basic Data Set (ISCIPDS:B)[483]

Type of pain	Definition and description of pain
MSKP (nociceptive)	Refers to pain occurring in any region where there is at least some preserved sensation above, at or below the neurological level of injury and which is believed to arise from musculoskeletal structures. The presence of this type of pain is suggested by pain descriptors such as dull or aching pain related to movement, tenderness of musculoskeletal structures on palpation, response to anti-inflammatory medications and evidence of skeletal pathology on imaging consistent with the pain presentation.
Visceral (nociceptive)	Refers to pain usually located in the thorax or abdomen and believed to be generated in visceral structures. The presence of this type of pain is suggested by characteristics such as dull, aching or cramping and a relationship to visceral pathology or dysfunction, for example, infection or obstruction.
Other (nociceptive)	Refers to nociceptive pains that may be present but do not fall into the musculoskeletal or visceral categories.
At-level (neuropathic)	Refers to neuropathic pain presenting in a segmental pattern. It is perceived anywhere within the dermatome of the level of neurological injury and three dermatomes below this level. It is often characterised as burning, electric or shooting. Sensory changes such as allodynia or hyperalgesia within the pain distribution are often found. The pain may be unilateral or bilateral.
Below-level (neuropathic)	Refers to neuropathic pain present in the region more than three dermatomes below the neurological level of injury. It has typical characteristics such as burning, electric or shooting qualities and a diffuse, regional distribution. Sensory changes such as allodynia or hyperalgesia may be present.
At- and below-level (neuropathic)	Refers to the case when a person with below-level neuropathic pain also has neuropathic pain within the region three dermatomes at or below the neurological level of injury but is unable to distinguish two separate pain problems.
Other (neuropathic)	For a neuropathic pain to be classified as SCI-related pain, a lesion or disease affecting the spinal cord or nerve roots must be present and the pain must fall within an expected anatomical location for that lesioned or diseased spinal cord or nerve roots. Neuropathic pain that cannot be attributed to a lesion or disease affecting the spinal cord or nerve roots should be classified as 'other' (neuropathic).
'Unknown'	Should be used when it is not possible to classify the pain into one of the categories listed above.

Abbreviation: MSKP, Musculoskeletal pain.

2.1.8.3 Pain as a personal experience

Earlier in Section 2.1.8.1, it was mentioned that during the 19th Century scientists started emphasising that attention to pain should be paid by listening to the patients'

symptoms. Today this is the standard and according to IASP[220] the patient's report on pain, even in the absence of any tissue damage or pathophysiological cause, should be regarded as pain.

A number of questionnaires have been developed aiming to capture the experience of pain. Though its mechanism still is not completely understood, it is known that the experience of pain is impacted by many personal, biological and psychological factors and its expression is a subjective matter. Pain has three psychological dimensions, 1) the sensory-discriminative, 2) the affective-motivational and 3) the cognitive-evaluative.[305]

2.1.8.4 The importance of pain quality and intensity

Collecting information about the quality of pain, as shown in Section 2.1.8.1, has in reality been done since ancient times using verbal descriptors. The importance of collecting information on the quality of pain is now highlighted and recommended.[483] As seen in Table 2.1.2 above, verbal descriptors help to classify pain in SCI.[404,406,407,483]

It is essential, together with quality, to measure the intensity of pain. Measuring these variables is a gold standard for measuring the effects of treatment[46] and understanding what treatment needs to be applied.[45] The information about the intensity of pain in SCI is mixed as, on the one hand, it is found to correlate with the cause of injury[381] and, on the other hand, no such correlation is found.[55,422] Irrespective of age[55,422] or gender[50] or level or injury,[457] people report similar intensity or severity of pain though in the adolescent general population girls report higher pain intensity[219] and also in SCI women tend to report higher, but not statistically significant, pain intensity.[57] In general, males are found to tolerate pain more than women and pain tolerance decreases with increasing age.[497] Females are reported to have lower pain thresholds and thus report greater sensory pain than males.[241] People with complete SCI report more intense pain,[374,381] but a trend towards people with incomplete injuries to report higher sensory scores than those with complete

injuries[451] has been found. Despite the similarities or differences in the characteristics of people in pain it can persist regardless of the use of medication.[13]

2.1.8.5 The importance of pain extent

Location of pain in SCI, and other conditions, has been recorded more regularly over the past few years and its relation with other variables like the quality,[488] the duration,[380] the intensity,[457] and the type of pain[484] that are sometimes reported help to gain a better understanding of the experience of pain in SCI. People with SCI may report a mean of 3.4 (±SD 1.8) areas with pain[488] and only up to a third of participants have only a single-pain site.[59,316] In people with chronic pain, including LBP, longer duration of pain and increased intensity of pain relates to an increase in pain extent.[59,254] There is no such information for people with iSCI and this study will investigate the relation of the extent of pain with regard to a number of variables including LBP, QoL and function. It would appear reasonable to expect that dealing with more painful areas on the body would interfere with the experience of pain.

Carnes et al[59] mentioned that two-thirds of their sample had multi-site pain, which did not meet the definition of chronic widespread pain, and pointed out that the impact of multi-site pain on QoL, health care and mental health may be greater than widespread pain. This can have implications for work abilities as people with multi-site pain perceive themselves to have less work ability compared to those with single-site pain.[316,329] A treatment aiming to target one single pain site, when the person suffers from multi-site pain, may fail to be effective if the other pain sites are not addressed, thus understanding multi-site pain is important.[59]

2.1.8.6 The importance of pain onset

It is well accepted that pain is an unpleasant experience therefore it is a logical assumption that an unpleasant experience that lasts a long time or starts early would create negative feelings and will affect various aspects of the life of the person living

with pain. Chronic pain is common in SCI and the onset of pain may be a factor that influences the experience of pain. The time of the onset of pain following SCI is often reported in studies but the extent to which this relates to the experience of pain or QoL and function is limited. It is known that in SCI the onset of pain post injury is at a similar time in both males and females,[50] it can be early, within the first six months following injury[12] for 50% or more of people.[90,488] On other occasions onset may be slightly beyond one year post injury[406] though for certain pain types, like MSKP, may have an early onset, which drops and then increases again.[406] LBP in SCI has also been reported early post injury.[371] Early pain onset is associated with higher pain intensity.[488] Intensity of pain affects the experience of pain, therefore this study will record pain onset and explore its relation with the experience of pain but also with QoL and function.

Summary of the experience of pain

In summary, in order to understand some of the theory behind this thesis it was essential to do a historical précis to understand what brought us to the current knowledge of pain and look at what constitutes the experience of pain in general, and in SCI, in particular. As scientists themselves state, there is still a lot that is not known about the mechanism of pain. What is accepted is that pain is a multidimensional experience, subjectively reported by the individual and has many factors affecting it including psychological and cultural ones. The next step is to review how prevalent the pain experience is in the population of interest.

2.1.9 Pain in Spinal Cord Injury

2.1.9.1 Prevalence of pain and general characteristics

The prevalence of pain in SCI has been reported to range from 26% to 96%,[12,13,58,115,240,317,331,380,381,427,446,451,470,489] with many studies placing it above 70%[58,317,331,380,381,451,489] similar to percentages reported by Burrell in the early 20th century.[52]

In SCI the main pain-related problems are caused by chronic pain[482] and severe chronic pain affects 25-43% of people.[53,489] The prevalence of chronic pain in the community has increased by around 10% in four years (1996 – 2000) and more than three-quarters of those with pain had persistent pain.[133]

Gender is one of the factors that may affect the experience of pain, and females are reported to have lower pain thresholds and pain tolerance[148,241] and they report pain more often[115] and of higher severity.[57] One mechanism to explain the sex differences is the "psychosocial" one in which the female role allows acknowledgement of pain whereas the male role discourages it.[149] Biological and environmental mechanisms can exist and result in the behavioural responses of the sex roles with regard to pain perception.[149] Hormones, particularly, oestrogens are suspected to be the modulators of pain even though it is not concluded if they worsen or alleviate pain, possibly doing both depending on the chronicity and the type of pain but also on the level of the oestrogen.[87] Cognitive factors may affect pain differences among sexes, for example, coping strategies, catastrophising, depression, post-traumatic stress, and anxiety are all usually more common in females and relate to higher levels of pain.[149,179] Other reports say that sex-related differences in MSKP are not explained by age, or even physical activity and catastrophising.[491] Other factors that may affect gender-related pain differences, however with conflicting evidence, are age (reduced tolerance to pain with increasing age), physical activity, family history, genetic factors and social learning.[147,149,491,497] In the general population some studies did not find any gender differences with regard to pain or back pain (BP).[383,444] Women may use more words to describe their pain thus disclosing more information on their pain experience.[426] Men and women describe their pain similarly with regard to the number of areas with pain, distribution, onset, intensity and pain influence on life satisfaction and no differences have been noted but women report significantly higher nociceptive pain.[48]

Patients may feel severe pain at the time of their SCI or just when they regain consciousness and never be pain free or, on the other hand, pain onset can be years post SCI.[33] Pain can be present in 25% of people with SCI by the first year of their injury

and increase to more than 40% by the third year.[230] It has been reported that pain in general is high following the injury but then decreases over the first six months.[407]

Regarding pain intensity people with complete paraplegia are reported to have more intense pain,[381] but no relationship between cause of injury and pain intensity is found.[55,422] Pain can persist even when patients receive pain medication and pain associates with spasticity.[13]

2.1.9.2 Brief causes, risk factors and consequences

Among the general risk factors for pain in SCI can be race and education level as more non-whites and more people with lower levels of education are pain free.[57] Older age at injury is another risk factor.[422] Pain is a common symptom in post-traumatic spinal deformity which often follows SCI.[47] Spasticity can cause pain and, in particular, MSKP.[500]

Pain can be associated with anxiety, distress, stress, low self-esteem, lower self-assessed health, fatigue, anger, family and social difficulties,[12,22,90,381,422] depression,[55,240,489] suicidal tendencies,[482] and negatively affects the person's mood.[406] It can interfere with sleep[90,381] lead to poor quality of life,[12,103] interfere with activities[427] and is related to spasticity,[470] which, in turn, affects function.[469] It has been reported that pain can interfere so much with the functional abilities of the person with SCI that it can take up to six months more to achieve independence in activities of daily living (ADL) compared to those with SCI who are pain free.[435]

The experience of pain is affected by its intensity and increased intensity of pain reduces QoL in the general population and in people with health-related problems, for example, AIDS,[387] as increased pain intensity relates to reduced well-being, increased depression and distress. Pain intensity interferes with daily activities and life control which then affects depression[15] and it contributes to developing chronic pain[15] via mechanisms probably explained by the neuromatrix model of Melzack (Section

2.1.8.1). Pain of higher intensity is related to catastrophising[51] and pain catastrophising is considered a predictor for poorer QoL.[257]

The relation between pain intensity and catastrophising has been shown in SCI too and greater catastrophising is related to greater psychological distress[450] and to decreased ability to deal with the pain.[488] As with other conditions similar to SCI, increased pain intensity has a negative impact on basic activities like sleep, mobility and self-care.[228] The pain with the highest intensity is the most disturbing[145] and higher pain intensity correlates with pain interference and mental health problems.[370]

The above findings illustrate the current beliefs about the complexity of pain and show the interaction of the psychological and the physiological effects on the pain experience. Widerström-Noga et al,[486] studying a group of people with SCI, concluded that even though increased severity of pain decreases life satisfaction its impact may be moderated by perceived social support. The social factor can vary in different cultures but is also affected by the health systems in place for each particular nation. The study by Widerström-Noga et al[486] came from a single country (the USA), while the current study investigates pain in three different countries. Though social factors will not be directly analysed, interesting questions may arise.

2.1.9.3 MSKP and LBP

Doing an online search of the literature using the combined keywords of "pain" and "SCI" plenty of papers are available to be read. When examining the papers in more detail it becomes clear that the vast majority of them discuss neuropathic pain and information on nociceptive pain is a lot less studied and tends to focus on MSKP involving the upper extremities.[7,92,196,322,459] Reference to MSKP is often made in papers discussing classification of pain in SCI.[19,58,381,406] Upper limb pain is studied in SCI examining shoulder pain and QoL[169,183,391] or function.[391] Recently, a randomised control trial used shoulder exercise strengthening to investigate shoulder pain in relation to QoL.[322,323] When location of pain is considered then LBP seems to be missed out. Whereas, when referring to "pain" in the general population, LBP is one of the

most commonly cited types of pain. This difference in the studying of LBP between the general population and the SCI population marks an obvious gap. In SCI it maybe that other types or locations of pain are of more importance, however the consequences of LBP will not be understood unless studied. Due to the difficulty in identifying related papers using a simple literature search, it was decided to address the question of LBP in SCI using a systematic literature search method. This will be presented in Chapter 3. Before presenting the results of the systematic literature search, it is essential to explain to the reader why LBP is an important location of pain and how it may relate to various aspects of patients' lives. To do this, LBP in the general population examining the three participating countries will be reviewed.

2.1.9.3.1 The problem of LBP

LBP is one of the two most common causes of disability in Western society,[238] accounting for seven million GP visits in the UK (in 1992-93).[11] Prevalence ranges from 12% to 49%[107,220,248,263] with one-year prevalence of 44%, point prevalence[4] of 27% and CLBP[5] of 21%.[358] The annual incidence is around 7%,[88,107] but can reach as much as 25%.[477] LBP prevalence slightly declines with increasing age.[358] Men and women are found to report similar percentages or women may report LBP slightly more frequently.[358,491] The prevalence of LBP in the USA has been rising over the past few years (period 1992 – 2006) to more than double for reasons that could include an increase in obesity, depression, awareness of LBP and reporting of it.[153] A rise in the one-year prevalence of LBP has been reported in the UK, from 36% to 49% with a consistent trend across ages, sexes, social classes and regions due possibly to awareness and willingness to report it.[346] In Greece, point LBP prevalence among office workers was 33% and life-time prevalence was 62%.[417]

[4] Point prevalence mean prevalence at the current time.

[5] CLBP is usually referred to as pain of at least three months duration.[220]

2.1.9.3.2 Location of pain

In the literature "back pain" is often used to refer to LBP. Some papers specify upper and lower back but often this is not the case. Unless a clear explanation is given of where on the back the pain is located, then it can be misleading to assume that "back pain" means "low back pain". In this thesis, the studies that report on "back pain" will be treated as a separate category of pain location to "low back pain". Back pain has been increasing over the last 10 years (by around 13%) in the UK but its severity remains the same. Possible cultural changes that lead to more awareness and willingness to report back pain are believed to be the reason for this increase.[346] Back pain can be the most common complaint in the general population (22.7%) rated first among men and second (after shoulder pain) among women and it is the most severe pain complaint in women.[26] In the elderly general population back pain can be even more frequent (48%).[496]

One of the questions that need to be answered when studying pain at any location is the type of pain. Treatment of pain relies to a great extent on the type of pain. In SCI two types of pain may arise; nociceptive and neuropathic as it was seen in Table 2.1.2. This study aims to focus on MSKP.

A number of the studies that report on MSKP in the general population include LBP as one type of MSKP though LBP is a location rather than a type of pain. MSKP is a common type of pain for every subgroup of the general population[358] making it an important type of pain to study. Over a period of 40 years, the prevalence of MSKP in the UK has increased again possibly due to people's willingness to report this type of pain, increased psychological distress and increased awareness by patients and health professionals.[192] In a Dutch population sample, the one-year MSKP prevalence was 74.5%, point prevalence was 54% and chronic musculoskeletal pain (CMSKP) was 44%.[358]

2.1.9.3.3 LBP recurrence

Unfortunately, LBP is a condition that often consists of more than one episode with recurrence percentages ranging from 34% to 42%.[88,348] Recurrence tends to happen in

people with longer lasting LBP and a tendency for more persistent LBP.[197] Even in adolescent schoolchildren recurrence can reach 59% and it is linked to impaired QoL and reduced physical fitness.[193]

2.1.9.3.4 LBP cost

Because LBP is common in the population it clearly has an economic impact on all societies. Indeed, the cost of LBP in the UK is estimated to be £1.4 billion in benefits, £480 million in health care and £3.8 billion in lost production totalling £5.68 billion.[152] These figures are rising as health care costs alone in 1998 were £1632 million[280] and the cost of lost production in industry in 1999 was £5 billion.[107]

2.1.9.3.5 LBP causes

Among the known causes of LBP are disc herniations, spinal stenosis, spondylolysis, spondylolisthesis or narrowing of the canal,[74,287,372,441,442] degenerative or congenital conditions, spine abnormalities like scoliosis, lordosis and kyphosis,[63,326,372,441,446] overuse syndromes,[301] mechanical damage/injury caused by abnormal loading, increased age,[248] imbalance of trunk muscle strength,[261] reduced physical activity and poor sitting posture,[301,326,441,442] and possibly changes in the CNS including changes in muscle tone and coordination and increased postural deviation.[210] People with scoliosis can report back pain (23%)[372] or LBP (30%).[420] Among people with neurological findings, like tight hamstrings, up to 42% report BP[372] and also lordosis (over 40°) is more commonly found in the LBP group.[420]

Lord[271] quoted Keegan (1953) saying that LBP can be a consequence of prolonged sitting possibly because of a decreased angle between the trunk and the thighs which results in flattening of the lumbar curve. Prolonged sitting with a poor posture is associated with the progress of LBP.[369] There can be two forms of poor sitting position; the flexed and the lordotic.[369] A flexed sitting position increases the pressure in the area and eventually leads to disc degeneration which can cause LBP[155,369] and a lordotic sitting posture which is less tensious and less harmful.[369] However, pain increases when there is lordosis of the lumbar spine and forward rotation of the pelvis.[466] Thus, a poor relationship between lumbar lordosis and the pelvis can

contribute to the appearance of LBP.[389] In addition, static posture aggravates pain.[466] Static sitting posture and prolonged sitting positions are experienced by wheelchair dependent people thus they often maintaining a poor relation between the pelvis and the lumbar area. Finally, it has already been mentioned that people with SCI may have secondary complications including scoliosis, lordosis, kyphosis or muscle imbalance (Section 2.1.7.5), thus contributing factors to the appearance of LBP can be vast.

2.1.9.3.6 Recovery from LBP

There is conflicting information regarding recovery from LBP. Some reports say that 90% of patients feel better after 4-8 weeks[441] or that 80-98% recover by 12 weeks[11,88,314] or even that the majority of the patients recover within 1-2 weeks.[441,442] Speed of recovery depends on factors like age, occupation[11] and severity of disability.[88] The patient's beliefs can influence recovery, for example, lack of confidence or the inability to cope with the problem may influence disability directly or indirectly.[314]

2.1.9.3.7 LBP risk factors

Factors that can influence recovery can also be features that could predict it, like factors prior to the onset of injury varying from psychological factors to work and physical activity or even physical appearance,[277] short duration of symptoms or sudden onset of symptoms.[277] It is important to be able to identify people who are at risk of developing chronic pain[197] and a number of prognostic factors are consistent among the reviews in the literature, including older age, increased psychological or psychosocial stress and worse baseline functional ability.[198] There seems to be a need to look wider and try to identify clusters of patients that fall under particular contributing factors that are overlooked like social and family support, benefits and health care availability.[197] Identifying these risk factors is essential to help treat the patient by providing counselling, planning, management and monitoring.[197] But also, as rightly stated "*the ability to predict which individuals are susceptible to long-standing LBP would be a major step ahead with regard to prevention*".[460] Studying LBP in SCI will help us to understand if being an individual with SCI is a risk factor for developing LBP.

2.1.9.4 Cross-national research and pain

Studies on pain, MSKP or LBP in the general population conducted in single countries have been regularly reported in the literature: in Sweden,[11,132] Denmark,[358,460] UK/England,[59,192,346,477] Canada,[35] Germany,[157] Singapore,[504] USA,[75,376,471] Australia[475] and Greece.[417,424] However, the majority of single-nation studies discussing pain in people with SCI have been done in the USA,[80,145,228,380,427,450,451,457,484,487] the UK,[240,374] Australia[406,407] and, occasionally, in other countries like Iran[371] and Turkey.[103] Studies looking into cross-cultural or cross-ethnic similarities or differences in pain, within one country have also been reported in the UK[206,346,444] and the USA.[130,379]

The number of studies discussing pain, MSKP or LBP either in the general population and more so in the SCI population using cross-national design, has been fewer. A study aiming to explore prevalence and severity of chronic pain, in the general population, in Europe included a random sample of around 50,000 people from 15 European countries plus Israel and found a chronic pain prevalence of 19%.[38] People in Europe reported pain of moderate to severe intensity which affected their daily activities, social and working lives.[38] They found some variations in the reported prevalence of pain between countries which they attributed to cultural differences within the countries and ways of managing chronic pain. Differences in the prevalence of chronic pain were observed among the countries; in the UK, 13% of people reported chronic pain and 24% depression, whereas in Norway, 30% reported pain and 28% depression.[38] This is very interesting as people with pain in Norway seem to have mechanisms (cultural or social) that maintain depression at low levels. Breivik et al[38] also found similarities between the countries like a lack of assessing pain by using valid pain scales. This is also important because comparisons of the results among countries are better enabled when using valid pain scales.

In another study conducted by WHO[182] across 14 countries, including Greece and the UK, the prevalence of persistent pain in the general population, and its association with health perceptions and psychological distress was investigated. Persistent pain was a common problem across the countries and associated with psychological problems but inconsistencies in the relationship between persistent pain and disability

across the countries were noted.[182] Greece was among the European centres that had relatively low prevalence rates and the UK was among the countries with persistent pain prevalence above 20%.[182] Gureje et al[182] found the back as the primary area with persistent pain. Persistence of pain is thus an important variable and it will be explored in the current study.

Finally, another study on MSKP in the general population across eight European countries, one of which was the UK, concluded that despite some differences between countries, the impact of MSKP and the perception of its treatment were similar across the countries.[498] This study showed that the prevalence of MSKP for people having constant/daily pain across the countries was similar (60-75%), and in all countries MSKP had a negative impact on QoL limiting the physical activities of daily living.[498]

The author of this thesis is not aware of any cross-national study conducted simultaneously on SCI to discuss pain in detail. Divanoglou et al,[121] in a cross-national study investigating medical complications following traumatic SCI in Greece and Sweden, reported on pain prevalence but did not expand further. They found no significant difference in the pain prevalence between the two countries.[121]

In summary, it has been shown that pain is a very common consequence of SCI and it has been studied mostly in single-nation studies. A preliminary examination of the literature showed that LBP has not been extensively studied in the SCI population, and though studies on MSKP do exist they refer to pain in other body areas. To verify the extent to which LBP (and related MSKP) is examined in SCI, a systematic literature review is conducted and described in Chapter 3. The second part of the current chapter will explore two important aspects of the lives of people living with SCI that have already been mentioned; QoL and function.

Part 2; Quality of Life and function

2.2.1 Introduction

The first part of this chapter, described the condition of interest, SCI, looked at the subject of cross-national research and reviewed what is currently known about the experience of pain. The presence of pain in SCI was reviewed along with LBP in general.

As mentioned previously, life expectancy following SCI has been rising in recent decades.[53,71,114] Though there are different reports about how much life expectancy has increased, in general researchers agree that people with incomplete injuries have a better life expectancy,[53,71,114] sometimes as high as 95%, if injured at a young age.[114] Consequently, improving the QoL of people with a disability like SCI, is essential. The direct consequence of SCI is a reduction of function and improving function is likely to improve QoL. This part of the literature will focus on these two important areas for the lives of people with SCI and will explore how they relate to the experience of pain.

2.2.2 Quality of Life definition

Skevington (1998)[409] quoting the WHO stated that QoL is defined as the *"individuals' perceptions of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns"*. QoL can vary between individuals as their subjective evaluation of it can be affected by cultural, social and environmental factors.[62]

2.2.3 Factors affecting Quality of Life

2.2.3.1 Personal expectations

Health-related QoL (HRQoL) is the health expectation one person has based on their experiences. Thus, even if the clinical condition between two people is almost identical, if their expectations are different then they may perceive their QoL differently.[62] Following a SCI though actual scoring on the QoL may not change a lot, people's expectation from the QoL may change.[354]

2.2.3.2 Time of measurement

The time of the measurement can affect QoL; QoL is dynamic and if the individual's health changes so does his/her QoL.[62]

2.2.3.3 Psychological functioning

QoL is reported to primarily be affected by psychological functioning and to a lesser extent by physical functioning.[412] Anxiety is associated with poor QoL and disability, and when it co-exists with a physical condition then the impact on QoL could be worse than the impact of the physical condition alone.[393]

2.2.3.4 Cultural background

One of the major factors affecting QoL is cultural background. In some cultures satisfaction is obtained via fulfilling material needs, whereas in others it is achieved via reducing them.[213] Hofstede developed six dimensions of national culture; 1) power distance, 2) individualism, 3) masculinity, 4) uncertainty avoidance, 5) long-term versus short-term orientations, and 6) indulgence versus restrain.[213] He concluded that different countries have different hierarchical needs and this should be taken into account.[213] These dimensions, though used extensively, have been heavily criticised as anthropologists and sociologists disagree with the equation of nation with culture and

they argue that within one nation there can be more than one culture.[20] As Smith summarised in his review,[413] Hofsdede argues that culture is deeply embedded and it is resistant to change. The belief by many that nation is not synonymous with culture has led to many people applying the Hofstede cultural dimensions at an individual level rather than at a national level[125,212] something that Hofstede criticised.[211] Another criticism of Hofstede's cultural dimensions has been the fifth dimension which was based on Confucian values, which Western societies find too oriental in nature and not applicable to the West, while oriental and Chinese societies believe that it is philosophically flawed.[144]

Magala[279] concludes that despite the criticism this framework it is the most widely acknowledged and used in studying cross-cultural differences. In this study, two out of the three (USA and UK) participating nations consist of more multicultural societies than the third (Greece). This study aims to describe differences and similarities between nations and will not examine sub-cultures within each nation. According to Hofstede's theory, the nation is the culture, but concerns raised in the literature regarding this concept will be taken into account.

2.2.3.5 Demographic characteristics

A number of demographic characteristics have been reported to be associated with QoL.

2.2.3.5.1 QoL; gender

Gender differences in QoL are found in SCI as women have lower mental health, health care or health satisfaction and they report lower HRQoL[252,349] despite being more comfortable with interpersonal relations.[252] They report better life satisfaction[116] despite reporting higher depression[252] across various races and ethnicities.[254] For women, in general, bad health is related more to the emotional and psychological aspects of life.[349]

2.2.3.5.2 QoL; age

Youth links with better QoL in general[349] as well as in SCI, as ageing with SCI leads to physical health deterioration.[260,438] However, no impact of age on life satisfaction has been reported[116] but age is reported to be associated with a decline in self-perceived health.[349]

2.2.3.5.3 QoL; level of injury

More serious injuries are found to result in lower life satisfaction[362] and people with tetraplegia report worse QoL.[313] However, Tatel et al[438] reviewing the literature found an inconsistency on the impact of the level of injury on QoL.

2.2.3.5.4 QoL; time since of injury

As the time since injury increases life satisfaction also increases[116] and QoL increases[481] for people with SCI or no such result is found.[362]

2.2.3.5.5 QoL; education

Education is related to QoL in SCI as those with lower levels of education report lower life satisfaction[116] which is similar to the general population.[349]

2.2.3.5.6 QoL; employment

The importance of employment resulting in better QoL is confirmed in people with SCI who report "occupation" as one of the three least satisfactory areas (along with sexual activity and pain relief).[239] Employment over the preceding year results in better QoL[260] and people who are employed report better life satisfaction.[116] Lower income is related to lower QoL.[349]

2.2.3.5.7 QoL; marital status

Marriage is positively related with better QoL after SCI, which again is similar to the general population.[438] Marriage is more vital in ageing with SCI.[438] Co-habiting improves life satisfaction[116,362] and single people report lower QoL.[481] Widowed people report bad health which is related more to the emotional and psychosocial aspects of life.[349]

2.2.3.6 Experience of pain

Despite pain alone not explaining variance in QoL,[219] the impact of pain on QoL is well recognised in the literature and included in QoL assessment tools e.g. WHOQOL,[226,409,410] EQ-5D[139,341] and the SF 36. Examining pain in relation to QoL is important and one of the main reasons for doing so is to gain insight into how people prioritise pain in relation to other QoL aspects and to explore how different cultures or people within the same culture think of the importance of pain.[409]

In the general population, pain and discomfort affect QoL by having an effect on a number of the components that constitute QoL.[409] Skevington[409] found seven such components, the most important of which were negative mood and satisfaction with and access to health and social care. Pain has been found to affect both mental health and physical functioning but the impact on mental health is greater.[235] People with various types of pain, like females with chronic pelvic pain[288] or pain due to Multiple Sclerosis,[235] or MSKP across many European countries[498] report lower general health[12] and HRQoL.[481] It is not only the presence but also the severity of pain which strongly correlates with a reduction in social functioning and mental health.[235] Gender differences on the impact of pain on QoL have been reported, as chronic pain is found to be related to anxiety and depression in females.[235] Women, in particularly elderly, with MSKP report worse health-related QoL.[26,69] Higher intensity of pain, more often reported by females, is also associated with lower QoL, especially in psychological functioning, in both genders.[219]

In SCI pain can be associated with poor QoL,[230,331] poor adjustment,[230] worse life satisfaction[49,362] and can cause distress in addition to that caused by the SCI itself.[12] Pain interference negatively influences self-reported life satisfaction, physical and mental health.[366] Pain in combination with low self-efficacy reduces QoL even further than each one individually.[331]

Earlier, when examining what constitutes the experience of pain (Section 2.1.8), it was pointed out extensively that pain is a subjective, personal experience which is affected by many factors. By definition (Section 2.2.2) QoL is also subjective and it is affected by

various factors including “concerns”. Since pain, when present, is usually a concern for the person in pain, it is understandable why pain negatively affects QoL. This explains the increasing interest in recent years for researchers to take the next step from just examining pain to investigating pain in relation to QoL. With this in mind, the current study will investigate the relationship between certain categories of pain in iSCI and their impact on QoL.

2.2.3.7 Other factors affecting Quality of Life

Other factors related to QoL but not requiring hospitalisation[260] include co-existing problems like respiratory problems and pressure sores,[362] problematic spasticity and bladder problems[481] and low mood and social functioning.[255] In the elderly population, it is reported that QoL depends, among other factors, on the physical functioning abilities of the individual[386] and, similarly in SCI, reduction of function leads to reduction in QoL.[446]

2.2.4 Cross-national research and quality of Life

Tate et al,[438] in reviewing the literature on SCI and QoL, concluded that the mixture of studies available from the USA, Canada and Western Europe enables interesting comparisons between the main groups and there is a fair consistency in what is a good QoL. Another important conclusion they made was that although people with SCI reported lower QoL than the normal population, their QoL was in general not as low as expected.[438] One point to take further from their study is that, at that time, most of the studies they reviewed came from developed countries where factors that positively affect good QoL, like education, social support and community integration, were improved compared to developing or underdeveloped countries. The studies reviewed in Tate et al[438] were single-nation studies though comparisons across the countries were enabled.

In a cross-national study on QoL in SCI (groups from Australia and Sweden), the predictors for QoL were very similar; mood, physical and social functioning and problems related to the actual injury.[255] Some differences within the system of each country may however affect the QoL of a person with a SCI. Kreuter et al[255] attributed the reported depressive feelings to the lower educational level. Lower level of education is often related to more physically demanding jobs, then people with SCI may not be able to manage such jobs thus exacerbating depression.[254] The author of this study is not aware of any study that discusses QoL in SCI in Greece thus the present research will provide interesting new information.

2.2.5 Summary of QoL

In summary, QoL is a very important aspect in the life of the individual. It is affected by personal, cultural and demographic characteristics but also by the experience of pain. The latter affects the QoL of all people with chronic disorders,[395] including those with SCI,[313,481] compared to the normal population. Interestingly though, often QoL in SCI is better than expected, though this usually depends on the severity of the SCI.[361] In general, QoL measures include some functional assessment of the person as it is thought to be an important element for what constitutes QoL. As expected people with SCI report lower scores on the function scale of the QoL measures and on general health but mental health and emotional health-related QoL scores are not as low as anticipated.[361] As problems with function are the principal direct consequences of SCI, the author of this thesis believes that when examining the experience of pain, function should be investigated in relation to pain and it should be examined using a tool specifically to assess function for this population, separate from a QoL tool, with the aim of addressing function in more detail.

2.2.6 Function and factors affecting it

As expected, people with SCI have worse function and well-being compared to the general population[481] and a number of factors may affect their function which will be reviewed below.

2.2.6.1 Severity of injury

Function in SCI is directly affected by the type, level and completeness of the injury as described in part 1, Table 2.1.1 of this chapter. Thus, functional recovery also depends on the level of impairment. People with an iSCI rate walking recovery as the most significant factor.[397] Walking recovery is "*the regained ability to walk independently in the community, with or without the use of devices and braces. It is also defined as functional walking*".[397] According to this review paper, 33% of people with a B lesion on the ASIA classification$_6$ may have motor recovery. People with incomplete motor injuries have a higher chance of walking recovery and up to 87% of people with paraplegia can recover two years post injury. People with iSCI syndromes, like Central Cord Syndrome and Brown-Sèquard, also have good functional outcomes.[397] Thompson[446] reported no differences in the level of injury in people with SCI who had a decline in function.

Using the keywords "incomplete SCI", "complete SCI" and just "SCI", while conducting an online search, there was a huge difference in the number of the results found. On one single search engine (the Google scholar©[174]) the number of papers returned when using the keywords "complete SCI" were about 10 times higher than those found when using the keywords "incomplete SCI". Clearly the focus in SCI studies has been on either complete injuries or studies that include both complete and incomplete injuries and pooled data together in one single analysis. The type of injury is one of the

[6] A B lesion on the ASIA Classification system is an incomplete sensory lesion: Sensory but no motor function is preserved below the neurological level and includes the sacral segments S4-S5.[9] For more details on all lesions see Table 2.1.1.

most significant factors to affect function, as mentioned above, and this study aims not to pool together data from people with complete and incomplete injuries but to focus solely on people with incomplete injury. The fact that people with incomplete injuries usually have better function must be taken into account when discussing, in later chapters, the results on function.

2.2.6.2 Demographic characteristics

In the general population, increasing age results in a reduction of the physical functioning and this reduction accelerates in older age groups,[21,94,352] though some recovery in function may happen the extent of which depends on the individual.[21] Women have a consistently greater decline in function with age than men[21,94] and are less likely to recover from a disability.[21] Reduced education[94,352] and non-marriage[352] are also related to reduced physical function in older people.

Age can be a negative prognostic factor for functional walking in SCI. However, people classified as having a C lesion on the ASIA classification system[7] and who are younger than 50 years old can achieve up to 90% of functional walking recovery.[397] Ageing with SCI leads to the need for more help with ADL activities, particularly in females.[266] In addition, older age at the time of injury negatively affects function in SCI as functional decline starts earlier than those injured at a younger age.[446] Finally, increased duration of injury is linked to worse physical function in SCI.[446]

2.2.6.3 Psychological difficulties

In the elderly, increased anxiety is found to relate to a reduction in functional status[119,428] and depressive symptoms are predictive of physical performance

[7] A C lesion is an incomplete sensory and motor lesion: Motor function is preserved below the neurological level, and more than half of the key muscles below the neurological level have a muscle grade less than 3.[9] For more details on all lesions see Table 2.1.1.

decline.[94,119,352] Poor self-perception of health status is also reported to relate to a functional decline.[119,428]

2.2.6.4 Physical activity

In the elderly, lack of physical activity and exercise are found to be associated with increased risk of reduction in functional status[94,428] and continued physical activity promotes physical function.[386] The benefits of physical activity and exercise are known in the literature for the general population but also apply to people with disabilities.[400]

2.2.6.5 Experience of pain

In the general population, pain and, in particular, MSKP results in functional and psychological impairment.[496,498] In the elderly population, those who report pain, including arthritis, joint pain and stiffness, also have reduced physical function.[94]

People with SCI and pain are found to have worse functional health status (measured with the Sickness Impact Profile Scale) and, in particular, the psychological dimension of the scale scored as worse.[362] In SCI people rate pain among the three top reasons for a reduction in their physical function.[446] Women with SCI attribute their functional deterioration to their MSKP (which they consider as a secondary complication to wheelchair use and ageing) and their upper limb joint pain.[353] Finally, people with pain and SCI require more assistance in achieving functional activities like dressing, bathing and shopping.[446]

2.2.6.6 Other factors affecting function

In the elderly, environmental problems like safety, lack of accessibility and problems with the neighbourhood including traffic, or inadequate lighting are related with a decline in physical functioning.[17,94,119] The reasons why function under these conditions can be reduced are self-evident as people would tend to be restricted

within their own homes due to the above mentioned problems. These problems could be faced by people with a disability like SCI, who are among a more vulnerable category of the population and problems like lack of accessibility or increased criminality could result in them reducing or not taking part in functional activities outside the home. Different countries may have different problems or the same problems at different levels, for example, in one country criminality may be a severe problem and in another lack of accessibility outside the home could be the main problem but in both cases the result would be the same for a person with SCI; restricting functional "freedom". Emotional support from a social network is found to predict better physical performance[400] and access to social networks for people with SCI can vary from country to country.

Among other problems relating to increased risk of a functional decline, there are also heavy alcohol consumption[428] and smoking,[428] while good nutrition status helps in promoting physical function.[386] Some medical complications following SCI, including skin and GI track problems can negatively influence function.[266] Finally, fatigue and weakness are among the three top problems leading to a reduced function in SCI[446] and women report increased fatigue and reduced energy levels more than men.[353]

2.2.7 Cross-national research and function

One large international study conducted in six countries, including the UK, examined function in people with SCI in order to evaluate the reliability and validity of a new version of a function scale (SCIM III) in a cross-cultural setting.[64,171] Another cross-national study conducted in Sweden and Greece, among others, looked at the function of people with traumatic SCI and found that people with a complete motor injury from Greece had inferior functional outcomes but no differences were noted for people with motor incomplete injuries.[122] No other cross-national studies in SCI to examine function were identified in the literature. As mentioned earlier, in Section 2.2.4, function measurement is often included in the tools used to measure QoL. But even

those studies which examine QoL, which would include some functional assessment in cross-national designs, are minimal.

2.2.8 Summary of function

In summary, function is the first aspect of the life of a person with SCI to be directly affected by the injury. The reduction in function depends on a number of factors that include both physical and psychological but also social ones like lack of accessibility. The experience of pain is one of these factors to negatively affect function and reduced function is related to reduced QoL. Thus, it becomes very clear why these three areas of the lives of people with SCI benefit from being studied together to identify relations between them. The number of studies on QoL in SCI is increasing, but there remains a lack of information on the impact of certain types of pain on function and, in particular, in cross-national studies or in iSCI.

2.2.9 Conclusion

This chapter discussed the importance of cross-national research and described the condition to be studied and the profile characteristics of people living with it. Studying the experience of pain is the aim of this thesis, thus it was essential to describe the philosophy and the theory behind it with a précis of what is known so far and how theories have developed through the centuries. A noticeable gap following a first look at the literature was that certain types of pain (i.e. LBP and to an extent MSKP) are not as often studied in SCI as other types of pain (i.e. neuropathic) and a more systematic examination of the literature will be needed to identify the information available. In contrast, LBP is extensively studied in the general population. The next chapter is devoted to systematically reviewing the literature in order to investigate how great this gap is.

The second part of this chapter explored two other areas of importance for the lives of people with SCI, function and QoL. The conclusion is that there is an increasing interest

by health professionals in studying QoL in SCI, but studies do not necessarily examine those three areas (pain, QoL and function) to establish relationships between them while using the same sample.

Two issues that rose while studying the literature which may affect the results in SCI are as follows: first, there is a tendency for studies to pool together data from people with complete and incomplete injuries (who may differ functionally) and often no comparison between them is made. Second, though there are plenty of studies that carry out cross-cultural comparisons within a single nation (e.g. the USA), there are few studies, in general, that follow cross-national designs.

Chapter 3; Systematic Literature Review

Chapter Brief Table of Contents

"Literature is at once the cause and the effect of social progress."

George Henry Lewes (1817 – 1878) English Writer and Philosopher

3.1 Introduction

In Chapter 2 it was explained that most of the papers discussing pain in SCI refer to neuropathic pain or when discussing MSKP they mainly focus on pain in the upper extremities of pain classification. In order to identify the reported prevalence of chronic LBP in SCI, the need to conduct a systematic search of the literature became apparent. Back pain has been included in the systematic search because often authors used the term "back" to refer to the lower back. MSKP was included in the search as long as it fitted the criteria of the study which will be explained later in the chapter.

Via a systematic review, the information available on a certain topic is identified, evaluated and interpreted by collecting primary studies in a secondary study.[243] In a systematic review, a pre-determined plan is used to collect information which includes a pre-plan protocol.[232] This protocol must include, for example, the study questions, inclusion criteria, search engines and data extraction.[232]

The systematic literature search which is presented in this chapter was initially conducted at an earlier stage of the thesis (in 2008) and has recently (2011) been updated to include up-to-date publications. This chapter will present the final search (2011) in the format as submitted for publication in a peer-reviewed journal.

This part of the chapter has been submitted, and it is currently under revision, for publication as follows:

Michailidou C, Marston L, DeSouza LH, Sutherland I. A systematic review of the prevalence of musculoskeletal pain and back and low back pain in people with Spinal Cord Injury.

3.2 Abstract

Study design: A systematic literature review between 1990 and 2011 in English speaking journal.

Objective: To review and summarise the prevalence of chronic back pain (CBP), chronic low back pain (CLBP) and chronic musculoskeletal pain (CMSKP) in people with spinal cord injury (SCI) and evaluate how pain is assessed.

Setting: Twelve databases were searched including CINAHL, Cochrane, Embase, Pubmed, and Science direct.

Method: One investigator reviewed the literature. Analysis was conducted using SPSS and Stata. Data were analysed using descriptive statistics and 95% Confidence Interval (CI).

Results: Eight studies fulfilled the inclusion criteria. Four reported on CMSKP, four on CBP and only two on CLBP.

Among people with SCI and pain the prevalence of CMSKP was 49% (95% CI 44%, 55%), CBP was 47% (95% CI 43%, 50%) and CLBP from two studies was 49% (95% CI 44%, 55%). There were variations in both the pain classification systems used and the data collected. The type of pain reported in the back and low back areas could not be established due to insufficient evidence.

Conclusion: The main finding is that the prevalence of CMSKP, and more particularly CBP and CLBP are not sufficiently reported in SCI literature.

3.3 Introduction

Medical advances over the last century have helped to keep people who sustain a Spinal Cord Injury (SCI) alive and life expectancy after injury now ranges from 33 to 44 years.[95] One of the most common and extensively studied consequence of SCI is pain. Pain is found to interfere with everyday life causing distress, stress, anxiety,[90,381,422] it negatively affects mood,[240,406,489] it interfers with sleep,[90,381] activities,[34,427] and quality of life (QoL).[230,331] Dijkers et al[115] conducted a systematic review on the prevalence of chronic pain after traumatic SCI and found a range from 26% to 96%.

The wide range of the prevalence of pain has often been attributed to the great variety of pain classifications used,[43,44,404] which can result in placing the same type of pain in a different category (one such example is given in Bryce & Ragnarsson, 2001[44]). This makes communication among researcher and clinicians difficult and comparison between studies impossible.[44] Often studies discussing pain management do not specify the type of pain treated, something Teasell et al[440] pointed out, highlighting the need for studies to examine the management of pain subtypes.

We agree with recent recommendations proposed by the International SCI Basic Data Set (ISCPDS:B)[483] that the location of pain needs to be assessed alongside the classification of pain. There has been a tendency for studies to discuss neuropathic pain or describe all types of pain together, and not report on pain location. When pain locations are reported they often refer to the shoulder or an upper limbs.[7,92,196,322] Chronic back pain (CBP) and, in particular, chronic low back pain (CLBP) are extensively studied in the general population and guidelines for treatment or prevention[5,54,325,394,461] have been published. In SCI a 60% prevalence of back pain[90] and a 30% prevalence of low back pain (LBP)[371] have been reported. People with SCI may expect to experience musculoskeletal pain (MSKP)[221] and its prevalence is around 60%.[406]

The importance of combining location and type of pain can be significant for the treatment of pain. Heat for pain relief in SCI has been proposed,[56] but guidelines for non-specific LBP tend to report that heat is not an effective treatment for LBP and do

not recommend it.[5] Thus, though heat may be considered as a pain relief for MSKP in SCI[56] it may be inappropriate when the pain is located at the lower back.

This study aims to systematically review and analyse the reported prevalence of CBP, CLBP and chronic MSKP (CMSKP) in people with SCI. It will also examine the types of pain reported in the back and lower back and how assessment is made. Unlike the review by Dijkers at al,[115] this review will examine studies that include people with any cause of spinal injury but will focus on specific pain locations (back pain (BP), and LBP) and pain type (MSKP). The research questions are:

For individuals with SCI:

1) What is the prevalence of CMSKP?

2) What is the prevalence of CBP and CLBP?

3) Is the reported CBP or CLBP neuropathic, nociceptive or both?

4) How are CMSKP, CBP and CLBP assessed?

3.4 Methods

3.4.1 Search strategy

A systematic search of the literature was carried out using the databases of the Centre for Reviews & Dissemination, CINAHL, the Cochrane Library, Embase (which includes Medline Ovid), Ingenta, metaRegister of Current Controlled Trials, OpenSINGLE, Pedro, PubMed, Science Direct, Scopus and Sport Discus.

Combinations of the following keywords were used:

- SCI, paraplegia, tetraplegia, and quadriplegia, CMKP, MSKP, CBP, BP, CLBP, LBP, back, low back, chronic lumbar pain, lumbar pain, pain site, site of pain, area of pain, and secondary conditions, prevalence, epidemiology, percentage, assessment, and measurement.

3.4.2 Inclusion Criteria

Articles were included if published in English between 1990 and 2010. An automatic alert was set up with the search engines to inform us of new, related publications. No such alert was sent out for papers published in 2011. The articles should discuss CMSKP in general in SCI and, if focusing on specific areas of pain, to refer to back and/or lower back pain. The study design was not a limiting factor for inclusion. The abstracts of all articles found to match the keywords were read (first stage of search) and, if relevant, the full paper was checked for eligibility to enter the review (second stage of search).

3.4.3 Criteria for allocation to research questions

To answer the first research question the studies should discuss CMSKP (≥3months duration). This could be one of three ways: 1) clear statement of pain chronicity, 2) use of a pain classification, 3) use of chronic pain measurement. If this was not clear then contact with the author was made and clarification was sought.

To answer the second and third research questions the studies should discuss CBP or CLBP (≥3 months duration). Finally, the selected papers should offer enough information to answer the fourth question about pain assessment. Table 1 in Appendix 1 describes these criteria.

3.4.4 Identification of studies

Initially 1729 papers matched the first stage of the search. Sixty-five keyword combinations were used but ultimately only 18 publications fulfilled the inclusion criteria to enter the review (Figure 3.1). Some of these papers were multiple publications or follow-up articles of the same study. In these cases we used the most complete report with the longest follow-up and referenced each "group study" under one publication; i.e. the five publications (Widerström-Noga et al.,1999;[489] Widerström-Noga et al., 2001;[488] Widerström-Noga, 2003;[484] Widerström-Noga and

Turk, 2003;[487] Cruz-Almeida et al., 2005[90]) are treated as one study and referenced under the latest reference 90 (Cruz-Almeida et al., 2005[90]). Another six publications (Jensen et al., 2005;[228] Hanley et al., 2006;[190] Raichle et al., 2007;[370] Molton et al., 2008;[318] Ullrich et al., 2008[457]; Turner et al., 2001[451]) are also grouped together and referenced under the latest reference 457 (Ullrich et al., 2008[457]). The 18 publications were part of eight different studies and their characteristics are described in Appendix 1: Table 2.

One study, by Loubser and Atkman[273] fitted the inclusion criteria, but was excluded as it can be argued that their sample was highly selective thus increasing the possibility of bias (people scheduled for intrathecal baclofen pump infusion for chronic pain for spasticity secondary to SCI).

3.4.5 Data extraction and analysis

A single investigator (CM) performed the literature search. Data extracted from the papers or given by authors was entered into the statistical package SPSS version 15.

I^2 was used to assess heterogeneity using Stata version 11.[204,418] We found that there was considerable heterogeneity in all prevalences considered; therefore, it was not possible to do meta-analyses. However, we calculated the mean prevalence and 95% confidence interval (CI) for the total number of participants by creating a "total-sample" for each pain outcome, similar to the method of Dijkers et al.[115] Doing so gives more weight to larger studies because there are more people contributing to the total than from smaller studies.[205] We used the total sample percentages to describe the demographic profiles and injury characteristics of the participating subjects.

3.4.6 Quality assessment

The quality of the study was not an exclusion criterion; however, a study quality check was carried out. The Effective Public Health Practice Project (EPHPP) quality assessment tool[131] was used but only for those aspects that were of interest; 1)

selection bias, 2) study design and 3) data collection method. In addition, we were interested in other aspects of the studies such as definitions and duration of pain, classifying pain according to types and dividing pain into location.

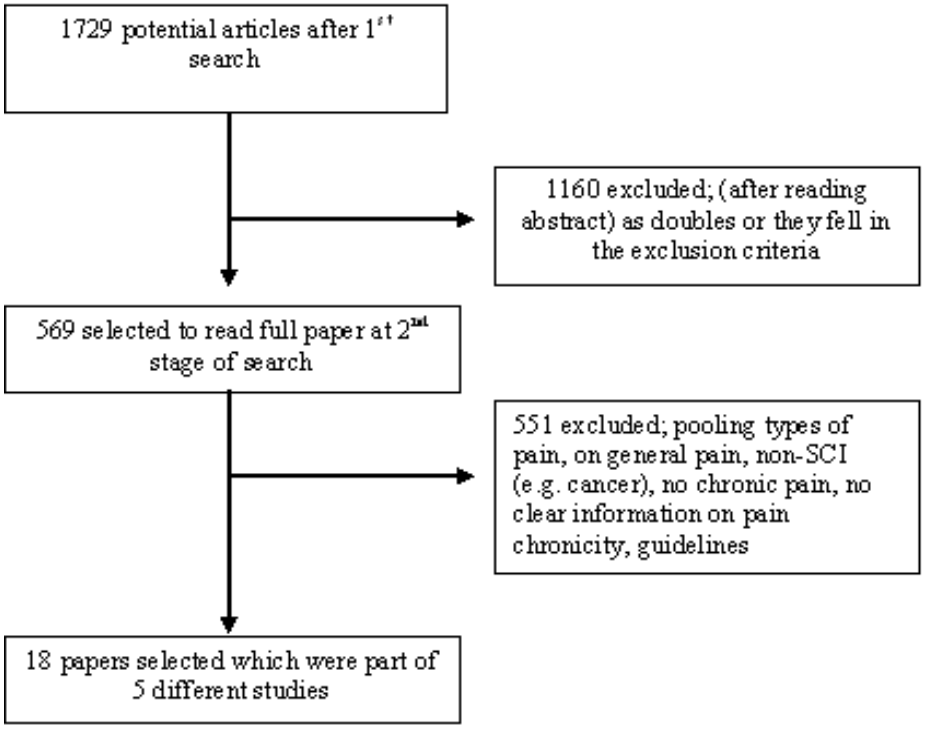


Figure 3.1: Identification of selected publications.

3.5 Results

3.5.1 General characteristics of studies

The studies were mainly surveys, either postal questionnaires or interviews, in many cases following a longitudinal methodology.[90,189,381,382,406,457] Many publications had a return rate above 70%[19,90,381,406,487] but others were below 50%.[228,318,370,457,489] Recruitment and random selection techniques were reported by some[58,381,382,451] but not usually explained. Only one study[228] compared the findings of their SCI sample to

national norms. According to EPHPP (selection bias),[131] the recruitment methods were "somewhat likely" or "very likely" to identify people representative of the target population.

There were no reports in these identified studies on the sample calculation or the profile characteristics of the people lost to follow-up. Only one study reported on missing data[90] and another on non-respondents.[489] Many studies lacked clear definition of pain chronicity and we had to either contact the authors or assume chronicity based on the assessment tools used. All studies reported on the main outcome measures and the statistical methods used. The tools used to collect data were in general both valid and reliable. The majority of the studies were well rated on the EPHPP, though the designs were rated as "moderate" or "weak". While a survey design is considered as a weak design by the EPHPP, it is commoncly used for exploring questions of prevalence.

3.5.2 Research question 1; What is the prevalence of CMSKP?

Four studies[19,58,381,406] discussed CMSKP. Table 3 in Appendix 1 presents the demographic profiles and injury characteristics of the participants for each individual study and for the "total-sample" created. Of the 453 participants[19,58,381,406] 76% (95% CI 72%, 80%) reported chronic pain and 38% (95% CI 33%, 42%) (172/453) reported CMSKP. Thus, among people with pain the prevalence of CMSKP increases to 49% (95% CI 44%, 55%) (172/344).

There was not enough data to check for differences in CMSKP based on the completeness of injury. Two of the four studies conducted physical examinations,[19,381] one used interviews to identify pain characteristics[406] and one[58] used a postal survey.

3.5.3 Research question 2; What is the prevalence of CBP and CLBP?

Under the study group referenced as Ullrich et al[457] the main participants' profile characteristics came from Turner et al[451] but information about the areas of pain

mainly came from Ullrich et al.[457] In the studies discussing CBP or CLBP[90,371,380,381,457] 1312 people participated but information was not always available for all (Appendix 1: Table 3).

3.5.3.1 Prevalence of CBP

There was a total of 1045 participants and 79% of them reported pain in general (95% CI 77%, 82%). Overall, 388 people reported CBP, which is 37% (95% CI 34%, 40%) of the total sample and 47% (95% CI 43%, 50%) of people with pain only.

3.5.3.2 Prevalence of CLBP

In the group study referenced under Ullrich et al,[457] LBP was discussed in two papers; Molton et al[318] and Ullrich et al.[457] Raissi et al[371] also discussed LBP (Appendix 1: Table 4). Of the 382 people with SCI (in the studies by Ullrich et al[457]) and Raissi et al,[371] 290 reported pain and 143 reported LBP. Thus, 37% (95% CI 33%, 42%) of people with SCI have CLBP which increases to 49% (95% CI 44%, 55%) among people with pain only.

The information available about the percentage of people reporting CLBP per level of injury could not be evaluated due to differences in data presentation in the studies. Ullrich et al[457] reported the highest LBP presence in people with high cervical injuries (69%), followed by people with paraplegia (64%) and last, low cervical injuries (51%). Among the studies examining CBP and CLBP two included physical examinations,[371,381] one interviews[380] and in the others postal surveys.[90,457]

3.5.4 Research question 3; Is reported CBP or CLBP neuropathic, nociceptive or both?

To answer this question the classification systems and verbal descriptors used in the studies[90,380,381,457] (Appendix 1: Table 5) were examined.

In the grouped studies referenced as Cruz-Almeida et al,[90] 64%[488] of their sample described pain in the back area as “aching”, a term mainly used to describe MSKP, and 61% reported “burning pain in the back”. “Aching” was found to be more common in people who marked the back ($p \leq 0.01$), or neck and shoulder ($p \leq 0.001$) on a pain

drawing. However, the authors confirmed that no distinction between pain types was made (i.e. neuropathic, MSKP) therefore conclusions about origin cannot be drawn. No information was given about LBP.

Rintala et al[381] used the Donovan pain classification system dividing pain into five categories and also dividing the body into five areas including the back, trunk and lower body. However, information about the type of pain in these areas was not provided. Rintala et al[380] and Raissi et al[371] did not classify pain by type, therefore identifying the origin of pain was not possible. Rintala et al[380] reported pain locations (which they categorised as above-, at-, below-level of injury) but they could not determine if pain was neuropathic or nociceptive.

Ullrich et al[457] discussed the finding that among people with BP, 67%[451] said that pain was worse with activity and 72% reported worse pain according to position. This may indicate mechanical factors contribute to the appearance of BP in this population.[451] Raissi et al[371] also found that BP was worse with activity and position and said that factors related to stability of the spine may cause or contribute to BP in SCI.

In summary, of the five studies reporting on CBP and CLBP,[90,371,380,381,457] only one used a specific classification system to describe the type of pain and this only discussed CBP.[381] Therefore, we did not have enough data to answer the third research question.

3.5.5 Research question 4; How are CMSKP, CBP and CLBP assessed?

All the studies discussing CMSKP[19,58,380,406] used a pain classification system (Appendix 1: Table 5). Cruz-Almeida et al[90] proposed a classification system in which MSKP was defined as mechanical spine pain (pain in the back or neck affected by activity and position) and overuse pain. Rintala et al[381] used the Donovan classification and MSKP was defined as pain secondary to stimulation or irritation of nociceptors within bone, muscles, and soft tissues. Siddall et al[406] used a classification system, which they had developed previously, that defined MSKP as “pain that was dull, aching, worse with movement or exercise, and that appeared to be arising from musculoskeletal structures”.

Intensity of MSKP was assessed by a Visual Analogue Scale (VAS)[19,406] or a Numeric Rating Scale (NRS).[19,381,406] Severity was assessed by the Verbal Rating Scale (VRS)[10,406] and location was assessed by a body diagram[90,381] and a pain location checklist[457] (Appendix 1: Table 6).

In the studies discussing LBP, the type of LBP could not be determined by the assessment conducted. To assess LBP severity, a list of adjective descriptors,[90] the VAS[58] and the NRS[371] were used. Finally, the NRS was used[457] to assess BP intensity (Appendix 1: Table 6).

3.5.6 Other related information of interest

Mean severity of MSKP was found to be 54 (SD 22) on a 0-100 NRS scale[406] and mean maximal intensity 3.5 on a 0-5 NRS.[381] No statistically significant difference in MSKP in people with complete and incomplete injury was found.[406] Turner et al[451] reported a trend towards more people with a C5-8 and T6-12 injury having BP and Ullrich et al[457] found slightly more people with high cervical injuries reporting LBP. BP was the second most common (58%) area of pain (after shoulder pain)[228] and the most common area for persistent, bothersome pain (61%).[451] As duration of pain increased, BP was found to be more common (p=0.036).[380] Pain intensity (using NRS 0-10) for the back was 4.7 (for C1-C4 injuries), 5.1 (for C5-T1 injuries) and 5.9 (for paraplegia).[457]

3.6 Discussion

The main finding of this review is that the presence of CMSKP and especially CBP and CLBP, have not been sufficiently investigated in the reported SCI literature. This review found that nearly half of the people with SCI who have pain report CMSKP, CBP and CLBP. This is slightly higher than that found in other populations like multiple sclerosis and stroke where MSKP is found to be around 31%.[176,187,246] Since the lower back is an area included within the whole back area, it would have been expected that the prevalence of LBP found in the current review would be similar to or smaller than the

percentage of the total BP, which was not the case. This is due to the fact that the reviewed studies used different ways to collect data, often not differentiating between BP and LBP.

The studies examined lacked homogeneity thus meta-analysis could not be conducted, The first difference between the studies was the definition of chronic pain, which varied from ≥ 3 to ≥ 6 months[90,380,381] to not being reported at all and there was a need to seek clarification from the authors[90] or to assume that pain was chronic because of the use of the Chronic Pain Grade Questionnaire (CPGQ).[19,58,406,457] Lack of definition of pain chronicity resulted in the exclusion of six studies[230,240,293,435,446] originally identified. Had definitions been clear, we may have identified additional information for the research questions. Some studies pooled together data on acute and chronic pain. Five studies that came under this category were excluded.[124,158,407,466,469] Clear definitions of pain chronicity should be given.[115] None of the studies we excluded for lack of pain definition or data pooling was published after the paper by Dijkers et al.[115] Since their study was recently published (2009) it may be that if a new systematic review will be conducted in a few years it may be able to identify further new studies that will have defined chronic pain including CBP and CLBP

Another problem encountered was the pain classification systems used. Although accepted systems and other pain measures were used, the variety contributed to the lack of homogeneity. The different classification measures have been suspected of contributing to the wide variability in the reported prevalence of pain in the literature.[22] Even though pain classification systems and often pain locations were reported, the type of pain in the back and low back could not be clearly established. While pain classification systems may seem accurate in categorising pain, they may not be accurate in assessing the type of pain at specific locations, at least where the lower back is concerned, particularly when physical examination is not conducted. Some studies described pain in the back to be most likely of musculoskeletal origin but did not report particularly on LBP.[381,451]

The type and the level of the injury have been reported to relate to MSKP. Siddall et al[406,407] found that despite differences not being statistically significant, people with

incomplete injuries report MSKP more often. MSKP is felt in areas that have preserved sensation,[405,483] thus in complete injuries it is felt above the level of injury, and in incomplete injuries it can be felt above or below the level of injury.[56] This means that for LBP to be considered of MSKP origin the injury should be either incomplete or, if it is complete, it should be paraplegia below the lower back level. The studies included in this review did not provide sufficient information about the level or the completeness of the lesion, or location of pain to allow calculations to be done for the "total-sample" or to draw adequate conclusions about the type of pain. Ullrich et al[457] reported a similar percentage of LBP for people with different levels of injury but did not clarify the type of pain. Cardenas et al[58] proposed a classification system in which MSKP was divided to include mechanical spinal pain (pain in the back or neck affected by activity and position) and overuse pain. This is an effort to put musculoskeletal back pain into one classification category, however, it still lacks separation of upper and lower back. Studies need to report more detail on the injury characteristics of their participants in order for the readers to be able to form a clearer idea of the type of pain at certain locations.

Lack of understanding of the type of pain in the lower back may have consequences for the treatment prescribed. Current published pain treatment in SCI is based on the broader pain categorisation and mainly dealt with using medication. Recently, authors have pointed to a need to improve pain treatment in SCI and that this should include other modes of therapy like strengthening exercises, massage or heat.[56] But heat is not appropriate for use when the area is not innervated[56] and a LBP strengthening programme may have to be adapted to take account of the non-innervated muscle groups. Recommendations for the treatment of MSKP in SCI have been reported[405] and guidelines for the treatment of LBP in the general population exist.[5,325,394] The lack of knowledge of the type of pain in the lower back may lead to non-effective treatment or maltreating the area. However, it should be mentioned that this review did not systematically examine the literature for studies offering *treatment* for CMSKP, CBP or CLBP in SCI. The collected data cannot conclude that these categories of pain are treated appropriately, or not, in clinical settings. The lack of reporting the type or presence of pain in the lower back may be an indication of a gap between what may

happen in a clinical setting and what is published. The best clinical decisions are taken from evidence-based information which is formed by the critical appraisal of the evidence.[390] Thus, if there is lack of such evidence treatment may be affected.

Despite BP being the second most common[228] or the most common[451] pain in SCI which increases, along with MSKP, at five years' post injury,[406,407] it has not received sufficient attention in the literature. On the basis of our results the prevalence of LBP is also infrequently studied.

Another point worth bringing to attention is that the profiles of the participants vary in some studies; some only reported on males[381] or people with pain only[58,273] or special groups.[273] Rintala et al[380] recruited the second largest sample which consisted of veterans. They reported the highest (together with one other study[406]) prevalence of chronic pain (81%) but did not report on MSKP. Veterans are often affected by Gulf War Syndrome (GWS) or Post-Traumatic Stress Disorder (PTSD) and can be found to report pain as a consequence.[18,480] Though most studies recruited people from the community, there was still variability in the participant profiles making generalisability more difficult.

Three studies[19,371,381] included physical examinations and the others relied on self-reported information about pain. Physical and/or radiographic examination help understand pain better. If these are not done then researchers should use other tools (e.g. body chart and classification systems) that are able to capture all types and locations of pain and discuss the combined information collected by such tools. Using the ISCIPDS:B[483] in new studies will help address such issues.

The purpose of the papers reviewed was to study the specific population of SCI so no comparisons with the general population were made. Only Jensen et al[228] compared SCI to national norms and found that people with SCI have significantly more severe pain which is an important finding. A future study that compares people with SCI to healthy individuals who may maintain prolonged positions with fixed or altered postures, and focuses on BP and LBP characteristics, would add to the body of current knowledge.

Recently, research interest about the impact of pain on social functioning and the psychology of the person with SCI has increased. This has already been discussed in LBP in the general population.[63,152,281,468] The benefit of the "insider" description of the experience of pain by using in-depth interviews has been pointed out.[99] It is essential to include the patients' knowledge and pain experience in their clinical management, as it can change with progression of their symptoms.[151] It is possible that the combination of in-depth interviews with the ISCIPDS:B may assist further in identifying the most suitable treatment approach using traditional techniques as well as emerging biopsychological interventions to reduce pain.

In conclusion, studies in the future should include investigation of the presence and aetiology of BP and LBP in SCI and long-term follow-ups would be useful. Enhanced pain assessment will improve pain management. The different mechanisms of pain can influence the response to treatment,[487] thus it is important to know the mechanism. In addition, preventative approaches may not be implemented if health professionals are not aware of the likelihood of a person developing BP or LBP. For example, designing or improving appropriate devices and seating systems[151] and educating patients and health professionals on pain prevention and management.

One limitation of the review is that only publications in English were included. To our knowledge this is the first systematic review of CMSKP and, in particular, pain in the back and low back areas in SCI. In order to gain further evidence more studies are needed which will use standardised measures to examine the presence, intensity and origin of pain in the back and lower back and possibly compare SCI with other patient groups.

Chapter 4; Translation of the questionnaire

Chapter Brief Table of Contents

How would one correctly translate the phrase:

"It's all Greek to me"

in Greek to be used by Greeks who anyway master the Greek language and nothing "Is Greek to them"?

4.1 Introduction

During the past few decades interest in cross-national and cross-cultural studies has increased and the availability and expansion of online surveys makes them easier and more approachable to conduct. As a result, the need for correct translations becomes crucial.

In order to conduct cross-cultural studies the measurements that will be adopted have to be equivalent in both cultures.[181] In this chapter, the theory of the translation procedure will be reviewed in brief and recommended guidelines will be discussed. The procedure followed to translate the two parts of the survey from English into Greek will be explained thoroughly.

4.2 Theory of translation

Translation is defined as "*written or spoken rendering of the meaning of a word or text in another language*".[217]

Brislin et al[40] argue that questionnaire wording and translation go "hand in hand", therefore one of the requirements of a good translation is to have a well-written original document. The SCIM III, which was translated for the purpose of this study, has been standardised in English and its validity and reliability are therefore established. The English version of the socio-demographic questionnaire[8] was first pilot tested and then translated into Greek.

4.2.1 Types of document translation

In starting to explain the procedure of a translation, it may be helpful initially to discuss the features of a document to be translated as well as the characteristics of a translator.

[8] The English version of the full questionnaire can be found at Appendix 2.

Reiss[377] categorised text that has to be translated into four different types:

1. Content-focused text; relates to "what" the author says. It must provide effective communication and accurate information. The information has to be explicitly given in the target language taking into account the usage of this language. Content-focused text is judged for its grammatical, stylistic and semantic characteristics.[377]
2. Form-focused text; is about the aesthetic and artistic nature of the form and is judged for its aesthetic, grammatical, stylistic and semantic characteristics. The translator does not adopt the forms of the source language but tries to identify analogous forms in the target language.[377]
3. Appeal-focused text; has to be presented in a particular and explicit way often involving non-linguistic results. The text maybe changed considerably to present this type of information effectively.[377]
4. Audio-medial text; can also be classified under the above types of text and the translated text must have the same effect as the original text on the hearer.[377]

4.2.2 Characteristics of the translator

Sofer[415] listed a number of requisites for the translator, the most important of which are presented below;

1. The translator needs to have a complete understanding of both languages (source and target);
2. Must be familiar with the culture of the study undertaken;
3. Must be up-to-date with linguistic developments and changes;
4. An individual must translate from a language to their own native language because he/she will be more familiar with the native language. However, an exception can be made if the person has lived in more than one culture and speaks both languages fluently;

5. The translator should be effective in writing or speaking by using an easily understood vocabulary;
6. A translator ought to have or develop research skills and be able to identify references.

Reiss[377] mentions the extra-linguistic determinants that can affect both the original and the translated version of a text. Among them are:

1. The subject matter: the translator is required to be familiar with the field to a satisfactory level;
2. The audience factor: the translator should understand the original author's audience and make it possible for the target language audience to understand the text in same way, and
3. The speaker factor; this can affect the language of the original author.

As it will be noticed later many of the characteristics of the translator mentioned above, as well as the elements of the translation explained below, are closely linked with the methods of the translation used in the current study.

4.2.3 Elements of a translation

Prieto[364] states a number of recommendations for the translation procedure including:

1. Pay attention to using the best initial translation method (prefer bilingual) and use phrases common in both languages;
2. Pay attention to the selection of the bilinguals;
3. Criteria for the project should be established in advance of the translation;
4. Combine pragmatic, ethnographic and linguistic principles for the translation rather than aesthetic-poetic;
5. Use a proof-reader unfamiliar with the project who can identify possible differences;

6. Use criteria for quality control and compare for equivalency;
7. Pilot test by seeking feedback on the translated questionnaire from members of the target population.

4.3 Proposed translation methods and guidelines

Among the first people to discuss translation procedures back in the early 1970s was Brislin[39] who mentioned four different methods of translation:

1. Back-translation refers to the translation when the researcher prepares the material in one language which is then translated by a bilingual into the target language. Then a second, independent translator back-translates into the source language and the researcher can judge the quality of the two original language forms;
2. The bilingual technique where bilinguals take the same text or different groups take different halves of a text, in the two languages they know;
3. The committee approach occurs when a group of bilinguals translate into the target language and then they discuss the mistakes and produce a single text;
4. Pre-test procedure is done after the translation to ensure the accuracy of the text.

Guillemin et al[181] state that cross-cultural adaptation of a measurement relates to the quality of the translation. The adaptation follows two steps; the translation and then its adaptation which means combining the literal translation of the words and sentences and adapting them according to idiom, cultural context and lifestyle of the language translated into. They proposed translation guidelines following five steps: 1) forward translation, 2) back translation, 3) committee review of the translations and back-translations, 4) pre-testing for equivalence and 5) re-examination of the weighting of scores if relevant.

They recommend at least two independent translators to conduct the forward translation. The use of qualified translators is advised and they should preferably translate in their mother tongue.[181]

Guillemin et al[181] recommended having as many back-translations as forward translations. This step can help to identify gaps in the cultural target context and mistakes in the first translation. The back-translators should be translating in their mother language and preferably not be aware of the concept of the translation.

The work of the committee, according to Guillemin et al,[181] is to compare the original source and the final versions of the translation. It should consist of multidisciplinary members. Structured techniques to resolve inconsistencies should be used as well. The committee should ensure that the translation is comprehensive and should verify cross-cultural equivalence of source and final versions.

Using multiple methods rather than a single method when translating is recommended.[39,40,181] More recently, the WHO[501] published a document on the process of translation and adaptation of measures of instruments which consists of four steps: 1) forward translation, 2) expert panel back-translation, 3) pre-testing and cognitive interviewing, and 4) final version. There are many similarities to the recommendations proposed by Guillemin et al[181] mentioning that the forward translator should preferably be a health professional familiar with the terminology and pre-testing should be done on the target population.

Along similar lines, the Medical Outcome Trust[300] published minimal translation criteria using four steps of translation: 1) forward step, 2) quality control, 3) pre-test, 4) international harmonisation. They emphasise the importance of seeking authorisation from the source author and gaining insight from the source author in the translation procedure. Also the pre-test can be done with either monolingual or bilingual panels.[377]

4.3.1 Equivalence

There are some differences between the processes explained above but the major characteristics are similar. Checking for equivalency in translations is very important as it is the best way to know if any possible differences found between the subject groups are not due to differences in the items translated and discrepancies in the translations.[39]

Brislin et al[40] proposed five techniques by which equivalence of the translation to the original language may be checked:

1. Comparisons of meaning between the original and back-translated forms;
2. Comparisons of meaning, by bilinguals other than the translator, between the original and the translated form;
3. Answering questions written about the content of the original version; the questions should be answered correctly by people who have read only the target version;
4. Comparing performance to instructions written in the original and in the target language;
5. Administering both versions of a test or questionnaire to a sample of bilinguals.

If aiming for conceptual equivalence attention should be paid to: 1) semantic equivalence, which is the equivalence of the meaning of the words. Problems with it may mean problems with vocabulary and grammar, 2) idiomatic equivalence where equivalent expressions or items need to be found, 3) experiential equivalence where the situations of the source version should fit the cultural context in the target language, 4) conceptual equivalence.[181] Both the WHO[501] and the Medical Outcome Trust[300] recommend a quality checking based on conceptual equivalence when translating health-related instruments.

4.4 Methods of translation; general steps

In the case of a standardised assessment tool, a manual or guidelines for its translation might exist. However, there were no specific translation guidelines or manual for the SCIM III measure. In this project a combination of techniques, as reported above, was used. The primary aim was to use effective techniques (e.g. use of bilinguals, back-translation, a panel and professional or health-related translators) in combination with pragmatic factors including the resources available to the project, identification of collaborators and cost. Existing literature on translated measures into the Greek language was reviewed looking into characteristics of the Greek population (e.g. SF-MPQ[166] and the EQ-5D[505]).

General advice on the procedure was provided to all translators participating in any stage. Also they were advised to use the following aid tools: 1) English – Greek dictionary of medical terms,[312] 2) Greek- English dictionary of medical terms,[508] 3) Oxford English – Greek and Greek – English learners' dictionary[419,508] 4) Babylon online Greek – English dictionary.[16]

The forward translations were collected and checked by the PI_9 who combined them into one document. If more than one word was given to describe the same word of the original English version but had the same meaning, then the word given by more translators or the one closest to the English original was chosen. Where different translations occurred they were checked for errors based on: 1) if different words had same meaning, 2) if different words had different meanings. Also, the level of difficulty of translating the question was taken into account as well as the comments made by the translators. In cases where discrepancies could not be resolved as explained above, the PI met with the translators to discuss the differences as recommended in the literature to do in these cases.[32] If there were still discrepancies in the translation and in order to enhance the accuracy of the translation an expert panel was used as recommended by WHO[501] and a single complete version of the translation was finally produced.

[9] The PI (Principal Investigator) is the author of this thesis.

In other studies, for the back-translation either one professional translator[166] or more than one volunteer health-related professional was used.[32,505] However, the back-translators used in the current study were not, in origin, of the targeted language (English), as recommended in the literature, thus an external panel to assist in the process was involved.

All translators were asked to rate each question on a numeric rating scale 0-10 (0=very easy to translate – 10= most difficult to translate). Additionally, some information regarding their background was collected. Finally, all translations were pilot-tested by patients[32,166] or lay persons.[505] Further details of the translation methods are explained below.

4.5 Methods of translation; translation of SCIM III into Greek

The steps followed were:

1. Gaining permission to translate the measure into Greek;
2. Forward translation;
3. Back-translation;
4. Piloting of Greek version.

4.5.1 Step 1; Permission to translate measure

As suggested by the Medical Outcome Trust,[300] permission for the translation of SCIM III into Greek was granted by Prof. A. Catz who is among the members of the team that developed SCIM I and produced the following versions. Prof. Catz recommended the translation of version III which had been published shortly before our contact. Prof. Catz confirmed that set guidelines for the translation of SCIM III did not exist and gave advice on which method to follow.

4.5.2 Step 2; Forward translation

Lee et al[261] found a high incidence of error while assessing their translated questionnaire and they said that this may have been due to the fact that they had not used a professional translator for the forward translation but a bilingual health-related scientist.

To avoid such a problem, an independent, professional translator together with four volunteer health professionals, all of Greek origin, conducted a forward translation. Their personal characteristics and the reasons for choosing them were as following:

A professional translator, of Greek origin, who specialised in health and medical related documents. This particular professional translator was chosen because of his specialist knowledge of medical documents.

A surgeon urologist, of Greek origin, was chosen because of his specialist medical knowledge. The SCIM III contains elements related to the functioning of the person in the toilet, an area familiar to this translator.

Two occupational therapists, PhD holders and university lecturers, both of Greek origin, were selected due to their research knowledge and their advanced skills in dealing with written documents.

A physiotherapist and university lecturer with experience in neurological rehabilitation in clinical settings, of Greek origin, was selected because of his familiarity with the target population.

All the above non-professional translators had the common characteristic of being exposed to the culture of both languages as they had been living and working in the UK for a number of years but were born and educated in Greece.

The PI compared the similarities and differences of the translations and combined the five translations into one document. In cases where differences required discussion with the individual translator this was done on a one-to-one basis. A panel of two external health professionals was consulted if there were still discrepancies in the

forward translation. The panel consisted of two physiotherapists, of Greek origin, both MSc holders, living and working in the UK, one of whom was a PhD student. They were chosen for their professional skills and research knowledge.

The final version in Greek was then proof-read for clarity by a separate lay person who was independent of the study and any necessary corrections were done. Details of the forward translation are presented in Figure 4.1.

4.5.3 Step 3; Back-translation

One of the benefits of using back-translation is the ability to utilise the technique of "decentring" which means, if necessary, making alternations to the original text in the source language in order to accommodate the text in the target language.[39] This was not possible with the translation of SCIM III (because it was an already established, validated tool in the English language) but was an option for the translation of the socio-demographic part of the questionnaire.

Guidelines recommend that translators should translate into their mother tongue but Sofer[415] claims that an exception may be made if the person has lived in more than one culture and uses both languages frequently. This was the case with the two selected back-translators who, even though they were not of English origin, had been living in the UK for many years, obtained postgraduate degrees in the UK and worked in the country, therefore using the English language daily. One was a physiotherapist, of Greek origin, holder of a Master's in Neurorehabilitation, and working in a hospital. This person was selected as he was found to be able to combine research knowledge and clinical skills and he had experience of working with people with a condition of neurological origin. The other was a lecturer in Biosciences, of Greek origin, holder of a PhD with an extensive knowledge of dealing with written texts. To increase the quality of the translation both of the translators were independent of the study, not aware of the original English version or the purpose of the study.

Similar to the forward translation process, the PI checked the two translations and, in the cases of differences, the back-translators were consulted face-to-face. If there were still discrepancies, these were discussed with the external health professionals who were the same two people who participated in the forward translation.

4.5.4 Step 4; Piloting of the Greek version

The Greek version of SCIM III_{10} was piloted by five people all of Greek origin. This sample was a mixture of people with SCI and lay persons. They were asked to comment on items they found difficult, upsetting or confusing. All comments were reviewed by the PI and, as necessary, words were reviewed with the health professionals who participated in the previous steps of the process. Details of the back-translation and the pilot step are presented in Figure 4.2.

4.5.5 The role of the developers of SCIM III

The developers of SCIM were included in the translation process by giving advice/ clarification whenever needed. Collaborating with the team that developed an instrument is recommended by other scholars.[283]

4.6 Methods of translation; translation of socio-demographic part

The fourth part of the questionnaire consisted of questions collecting socio-demographic and other information and will be described in detail in Chapter 5. Here the focus will be on the translation approach only.

The steps followed in the design and translation of this part of the questionnaire were as follows:

[10] The Greek version of the full questionnaire can be found at Appendix 3.

1. Development of the questionnaire;
2. Pilot of the English questionnaire;
3. Forward translation into Greek;
4. Back-translation into English;
5. Pilot of the Greek questionnaire;
6. Amendments and finalising of the questionnaire.

The first two steps will be described in the next methodology chapter (Chapter 5). Similar to the SCIM III translation, the translators were asked to rate the level of difficulty of translating questions and were encouraged to provide comments. Figure 4.3 describes the procedure followed for the development and translation of the socio-demographic questionnaire.

4.6.1 Step 3; Forward translation of the socio-demographic questionnaire

Five professionals volunteered to conduct the forward translation and they were all different individuals to those participating in the SCIM III forward translation. One was an occupational therapy lecturer, of Greek origin, a PhD holder, who had lived and worked in the UK for many years. This person was chosen for her specialist skills in research and experience in dealing with written forms.

The next translator was a physiotherapist, of Greek origin, holder of an MSc and, at that time, a PhD researcher. She was one of the two members of the external panel for the SCIM III translation and did not serve as a member of panel in this translation.

One translator was a senior lecturer in Economics, of Greek origin, holder of a PhD, living and working in the UK for many years who was chosen for his extensive knowledge of dealing with and correcting documents.

The next translator was a business analyst, of Greek origin, holder of a Master's degree, who was chosen for his ability to look into the detail. This person was a

proofreader in the translation of SCIM III and did not act as a proofreader in this translation.

The final forward translator was holder of a BSc in business administration, of Greek origin, at the time completing her PhD in a UK university. This person was chosen because she had used cross-cultural, back-translation methodology in her research and was familiar with the procedure.

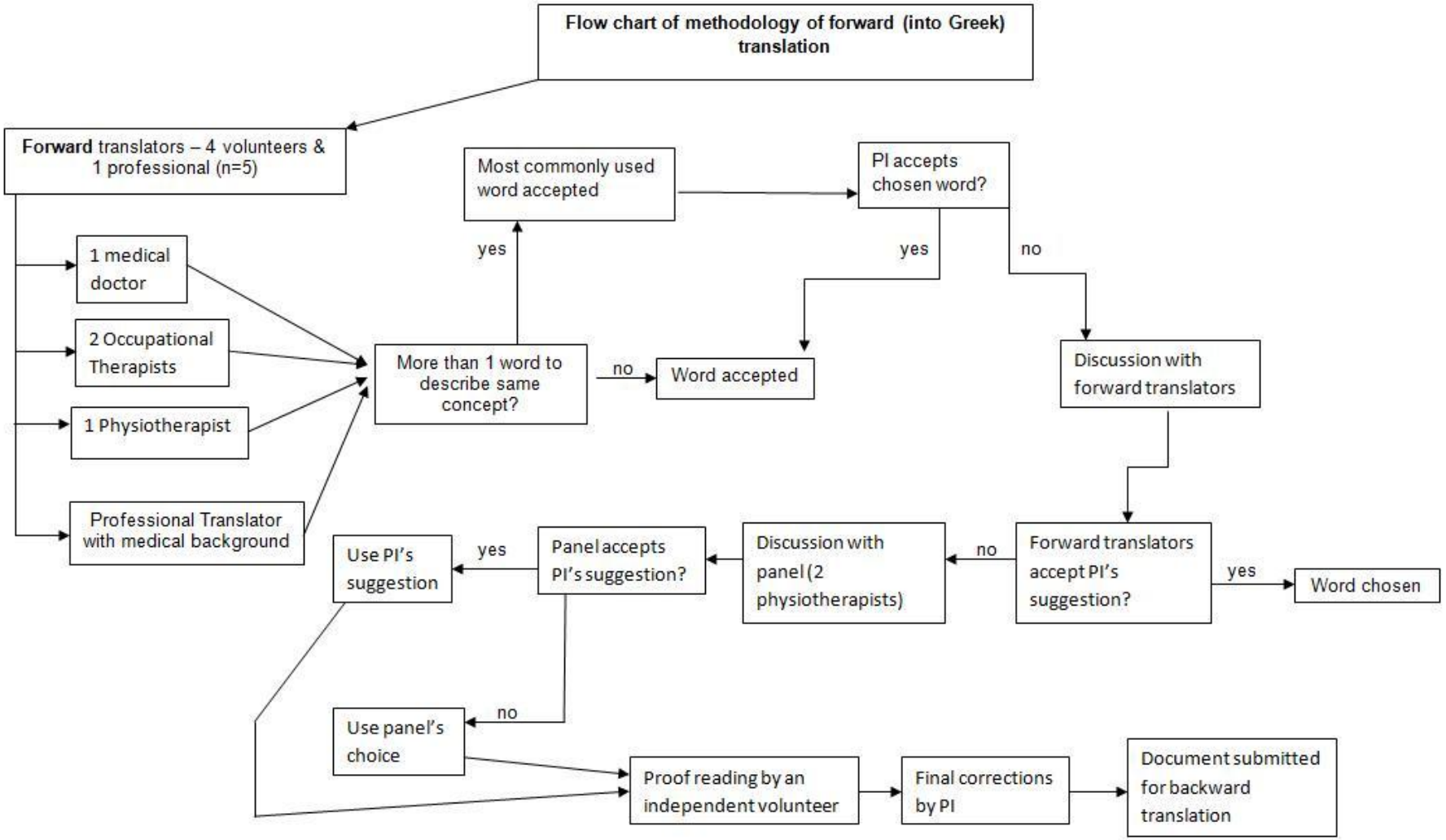


Figure 4.1: Flow chart of forward translation into Greek of SCIM III

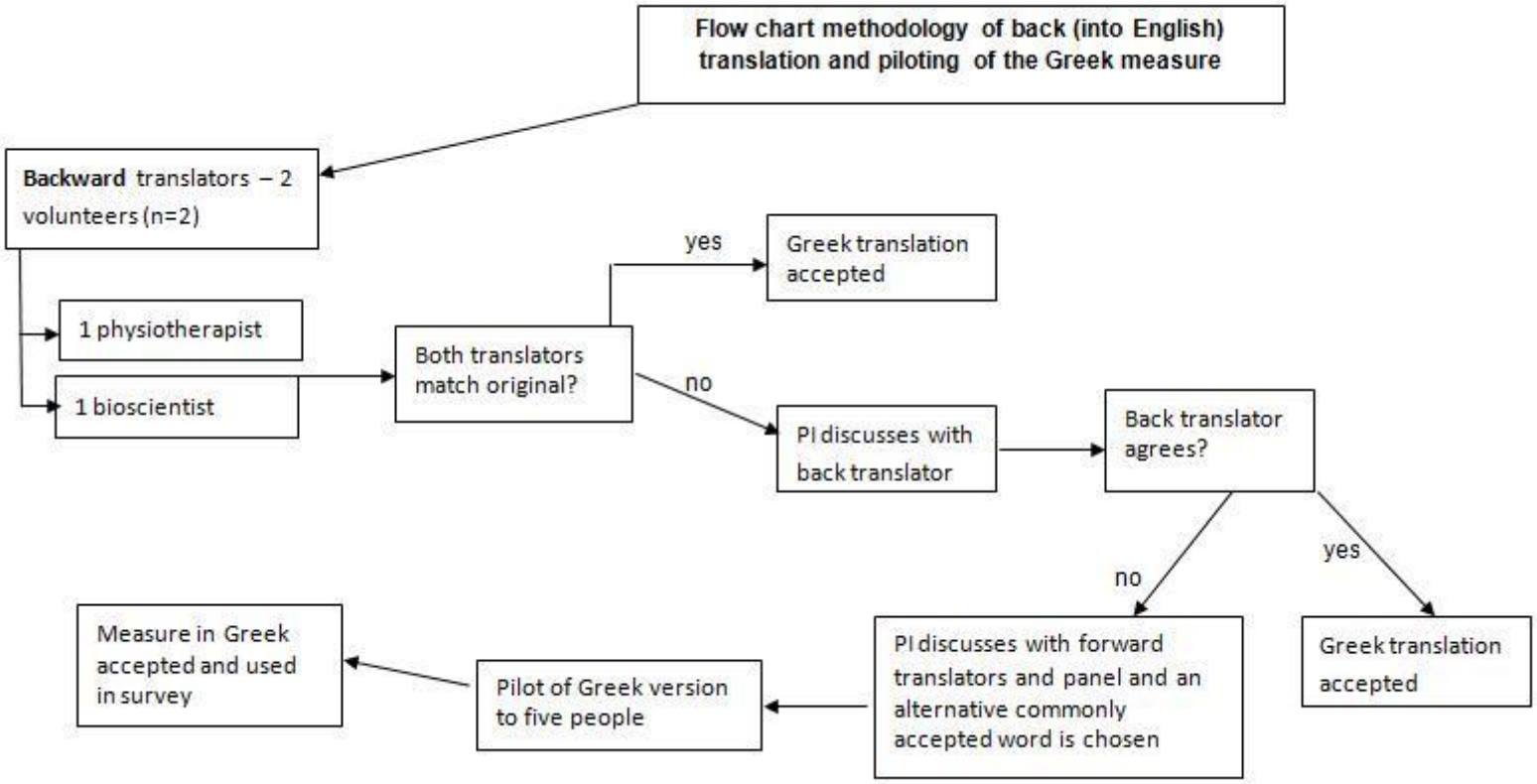


Figure 4.2: Flow chart of back-translation (into English) translation procedure of SCIM III

As with the procedure undertaken in SCIM III, all the above translators had the common characteristic of being exposed to the culture of both languages as they had been living and working in the UK for a number of years, and therefore used the language on a daily basis, but were born and educated in Greece.

The completed translations were cross-checked by the PI and a single socio-demographic questionnaire was formed. The decision of the final formulation of each question was taken based on the same general regulations that were pre-established and described in earlier pages. When it was necessary to discuss discrepancies with the forward translators this was done on an individual face-to-face basis and, if they were not resolved, the opinion of the external panel was sought. The external panel consisted of a physiotherapist, holder of a Master's in neurorehabilitation, of Greek origin, and who served as member of panel in the translation of SCIM III. A single document in Greek was produced out of the five forward translations (Figure 4.3).

4.6.2 Step 4; Back-translation of the socio-demographic questionnaire

A professional translator was not used in the forward translation of the socio-demographic questionnaire, but was used in its back-translation. She was an English teacher and translator, of Greek origin, who had been working as an English examiner, in the UK, for many years.

One single back-translation (into English) was made which was then double checked by the PI for errors. When necessary a discussion between the back-translator and the PI took place. Because there was only one back-translation an external panel of monolinguals of English origin was consulted. This panel consisted of four members: a research nurse, an occupational therapist and two clinical psychologists, all of whom had been working for the NHS in funded research projects. They contributed to the use of the decentering technique[11], assisted with any grammatical errors and decided on

[11] The "decentering" technique means making alternations to the original text in the source language in order to accommodate the text in the target language, as necessary.[38]

"disputes" on word choices between the translators. Figure 4.4 describes the back-translation process.

4.6.3 Step 5; Piloting of the Greek version

A group of five people piloted the Greek version of the questionnaire. They were all of Greek origin and were asked to comment on items they found difficult, upsetting or confusing. All comments were reviewed by the PI and discussions were held with individual health professionals who participated in the previous steps of the process.

4.7 Conclusion

This chapter has presented and justified the method followed to translate the two parts of the survey that were not available in the Greek language, 1) SCIM III and 2) socio-demographic related questions. Details of the proposed methodology for translations were described by looking into the existing literature and proposed guidelines. Two separate translation procedures took place and a methodological, step-by-step, procedure was carried out which included a mixture of techniques. Using the approach of mixing methods enabled choosing techniques that were found to be more appropriate for this study taking into account the resources available combined with sound methodology.

The next chapter will look into the methods employed to conduct the survey, will explain step-by-step the procedure followed and examine the related methodology.

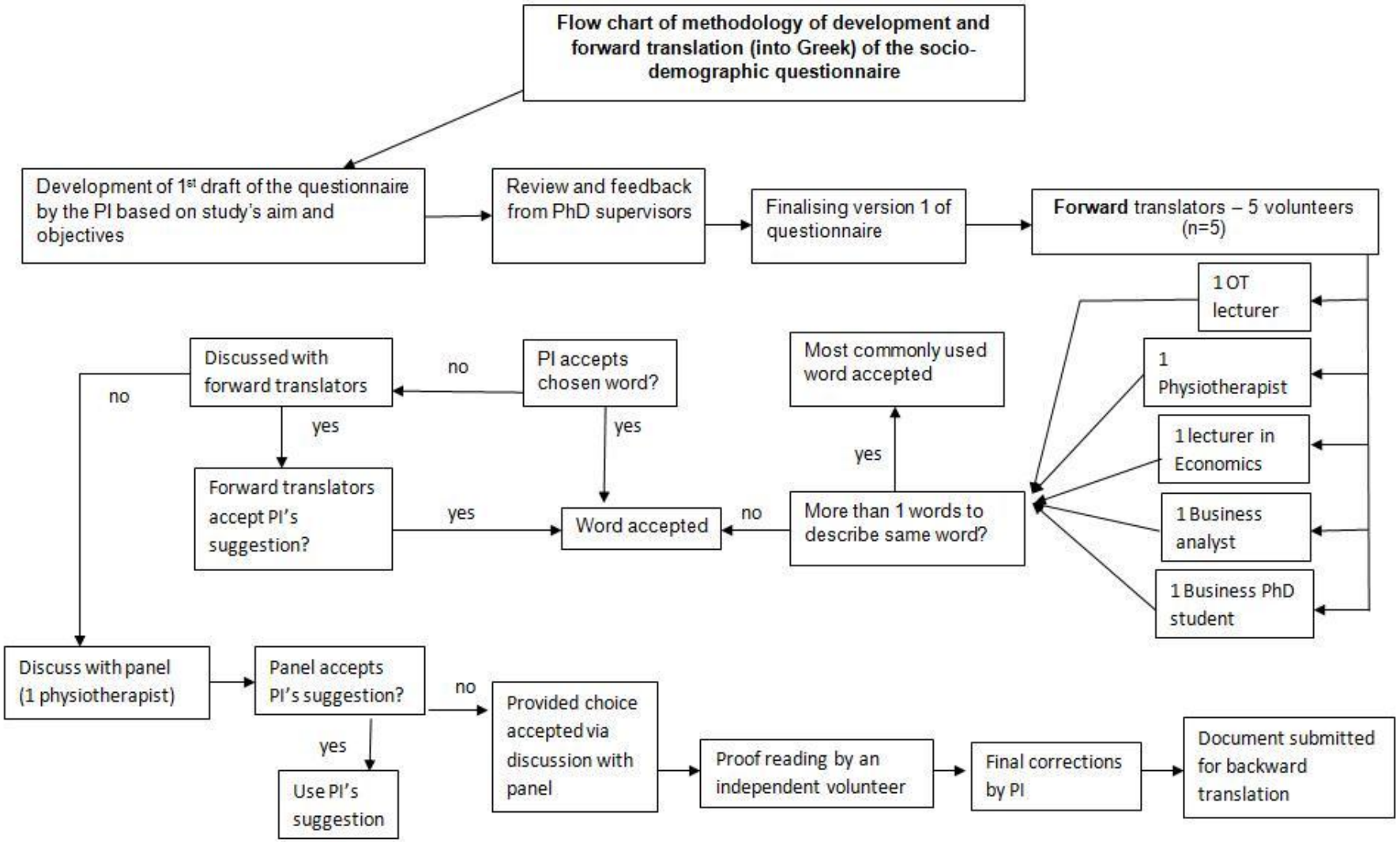


Figure 4.3: Preparation and forward translation of the socio-demographic part of the questionnaire

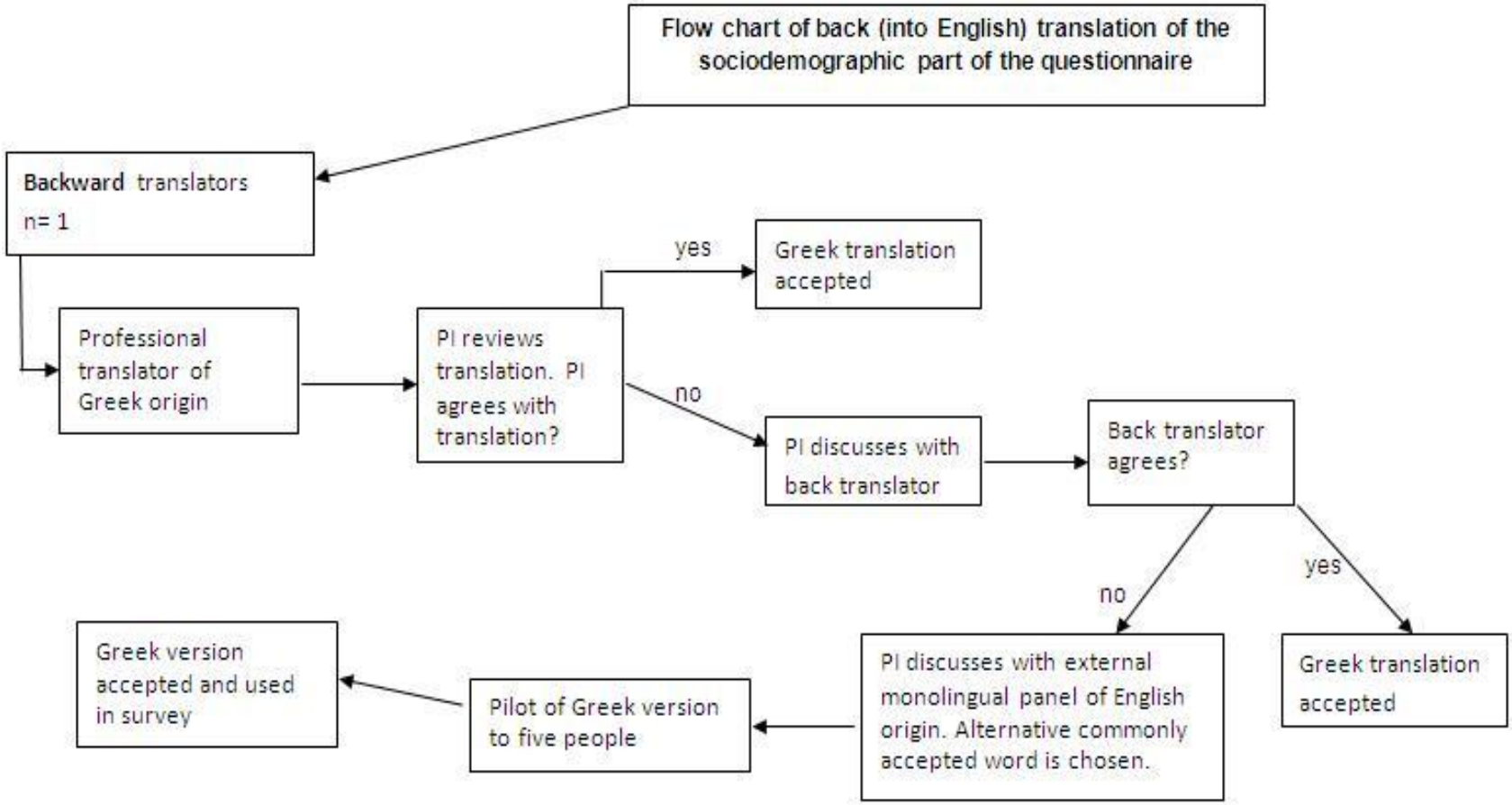


Figure 4.4: Back-translation of socio-demographic part of questionnai

Chapter 5; Research design, methodology and methods

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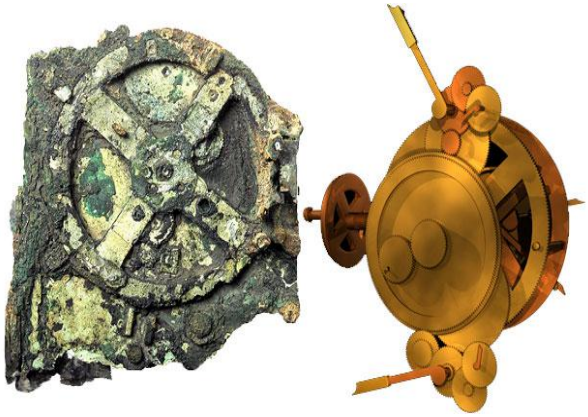

[12]"Every art and every science reduced to a teachable form, and in like manner every action and moral choice, aims, it is thought, at some good"

Aristotle (384 BC – 322 BC) – Greek philosopher[14]

[12] Picture taken from http://asymptotia.com: The Antikythera Mechanism is believed to be the first ancient mechanical computer. It was used in astronomy. It may be linked to Archimede's concepts. The mechanism was found in 1900 in the Antikythera shipwreck in Greece.

5.1 Introduction

The need for health studies to become more cost-effective, more efficient and maintain the scientific evidence is well documented. To achieve these goals, the design and the methods of any study need to be well prepared, well structured and evidence based.

The previous chapter described the methodology and the methods employed to conduct the necessary translations that were performed as part of the survey for this project. This chapter will describe the methods followed to conduct the survey while referring to the theory of survey methodology.

The study was conducted in three countries and the survey was primarily completed electronically (web survey) but also via the post (mail survey). An extensive presentation of the web survey, its benefits and the difficulties of conducting it will be made. The description and justification for both the web and the mail survey will be done in parallel with presenting the web survey process described by Fan & Yan.[143] The chosen method aimed to increase response rates and to reach the targeted sample size together with minimising, where possible, the sources of error. Finally, a methodology of the data analysis will be provided.

5.2 Research design; General

In order to make a research idea an actual plan, an understanding of research is required as various designs can be used to answer the same research questions, with various benefits. Therefore the best design is the one that is scientifically valid but also reconciles the goals and the resources available to this study.[347,357]

This project is a quantitative, correlational research study using descriptive and analytic survey methodology based on a cross-sectional, cross-national retrospective design collecting data using mixed mode research techniques of self-completed questionnaires primarily collected online (web survey) or of paper format (mail survey). The survey methodology has been widely used in epidemiological studies and

other studies aiming to identify prevalence on variables of interest within specific groups of people. It has been used extensively to study all types of health issues including SCI. Furthermore, the survey is the method most commonly used in cross-national research. Thus, selection of this type of method is in line with the general research methodology followed in the field. It also fulfils the aim of the current study. In the sections that follow this type of research is explained in detail and the reasons for its selection will be understood in more depth.

5.3 Research design; Survey design

A survey is a research approach used to collect information from a large number of people by using a questionnaire or an interview.[203] It has the "*ability to estimate, with precision, the distribution of a characteristic in a defined population*" but can be subject to sources of error including coverage, sampling, measurement and non-response.[117] Survey errors will be discussed later in this chapter.

A survey is descriptive or analytic where the descriptive answers the question "how many?" and the analytic the question "why?" A descriptive study looks at certain characteristics of the people studied, can test hypotheses and generate associations but cannot give evidence related to the cause. An analytic study uses inferential statistics to explore associations and test hypotheses, it is less orientated towards representativeness and more towards giving explanations and predictions.[36,285,342,347] The current survey will describe the participating group and will explore associations and hypotheses.

A correlation analysis observes the characteristics of the sample but makes no inference from them and[147] when the data is collected at one point in time, then this is a cross-sectional study.[36]

In a retrospective design, the events of interest happened before the onset of the study[347] but questions related to the current time can be included.[36] This type of design is commonly used in surveys.

Over the last few years technology and, particularly, the internet are increasingly used for professional and/or personal use and for research purposes including both questionnaires and interview techniques. The interview method is beyond the scope of this project and will not be discussed further.

5.3.1 Research design; Cross – national surveys

In Chapter 2 cross-national research was described in detail and it will not be repeated here. What can be added is that this type of research can often only be done following a survey methodology and so far there is limited practical guidance on international research.[195] Despite the disadvantages of being expensive, difficult, time-consuming and requiring good local collaborators it has the advantage of raising questions about the generalisations made in single-nation studies.[245] Certain steps can be used to reduce errors which will be discussed later in this chapter.

5.3.2 Research design; Mail survey

The first documented mail survey took place in 1788 by Sir John Sinclair who mailed questionnaires, consisting of more than 100 questions, to 938 parishes of the Church of England, sent 23 reminders and achieved a 100% return rate.[97] Sampling technique was first used in 1802 in France by Laplace.[97]

Mail survey has continued to grow and it is extensively applied in this type of research. Among its advantages are targeting a large number of people, reaching people in remote areas and collecting data internationally (Table 5.1). Studies aim to collect data while reducing errors and increasing the response rate. Of course, this is the aim for all types of research.

5.2.3 Research design; Internet survey

"The Internet is becoming the town square for the global village of tomorrow"

Bill Gates (1955 -) – Non-executive Chairman, Microsoft

An internet survey is "*the administration of the surveys via the internet, including distribution by email or electronic mailing lists, or posting the survey on web page*".[289]

Scientists had to respond to the development of the computer technology and shifted research methodology to use the means available[262] and the Disk-By-Mail-survey[13] was introduced.[97] Technology is developing rapidly and methodologists are constantly trying to "catch up" with the innovations, the latest of which is the internet survey[117] which is a promising type of data collection offering great opportunities but imposing challenges.[507]

There are two main categories: 1) the email and, 2) the web (based) survey and more than one technique can be used to collect data.[402] The email survey is when the questionnaire is delivered to its targeted population via an email attachment, completed and returned via email. The web survey is when the questionnaire is placed on the web (HTML:HyperTextMark-up Language), accessed by the respondents through an internet connection and via a web browser, completed and submitted online.[202] Often these techniques are pooled together in the literature under broad categories like "online survey"[402] sometimes causing difficulties in distinguishing some of the methodological characteristics. A web survey was used for the purpose of this project.

There are many advantages of the web survey. The growing number of people using the internet makes it an even greater tool to access large numbers of people including those of special interest[396] and it makes international data collection easier,[72] both of which were targets in the present study.

[13] Disk-By-Mail-survey is when a disc with the survey is mailed to the respondent who uploads it on the computer, completes it and returns the disc by mail.[95]

Another benefit is that cost is kept lower by reducing labour hours, paper, postage, printing, travel, faster recruiting.[77,278,432] An average response time of six days for a web survey is reported[77] and almost everyone replies within two weeks.[185] The cost factor contributed to the decision to follow this type of methodology for the current project.

Another benefit that applies to web surveys is maintenance of anonymity which can reduce the negative social effects of completing a survey.[202] Social desirability and political correctness may result in the respondents giving insincere but "correct" answers and a tendency to be more honest when faced with a computer has been suggested.[431] Using the tools of the internet survey immediate feedback on the return rate (RR) is provided[233] which may result in taking action, if needed, to increase it, which is another benefit of this method.

Improvements in technology enable all types of internet survey to be conducted via devices including mobile phones and Personal Digital Assistants (PDAs).[464] Most web surveys have techniques for transferring data directly into statistical packages or spreadsheets for analysis, therefore data entry errors can be eliminated[396] and data can be stored, used and re-used faster.[262]

All research methods, including online surveys, have disadvantages including limited coverage of the population, reduced control over responses, reliance on software, security-related issues and skewed demographics.[85,201,396,431,507] In later sections in this chapter the steps taken to minimise the disadvantages, eliminate errors and increase RR in the current project will be discussed. Table 5.1 summarises the advantages and disadvantages of surveys.

Table 5.1: Advantages and disadvantages of mail and internet surveys.

		Mail survey	Internet Survey	
			Email survey	Web based survey
Advantages	Can target large number of participants	Compared to interview	More than all methods	More than postal & interview
	Can reach people in disperse areas and of special interest	Compared to interview	Compared to all methods	Compared to all methods
	Easier collection of international data	Compared to interview	Compared to all methods	Compared to all methods
	Can be sent to various types of devices (phone, pc, PDA)		Compared to all methods	Compared to all methods
	Faster data collection		Compared to all methods	Compared to all methods
	Use of better design to motivate respondents			Compared to all methods
	Can secure greater anonymity		Compared to postal	Compared to all methods
	Respondents are believed to be more honest		Compared to postal	Compared to postal
	Can be completed in respondents own time & privacy	Compared to all methods	Compared to all methods	Compared to all methods
	Gives immediate feedback on response rate			Compared to all methods
	Less costly	Compared to interview	Compared to all methods	Compared to all methods
	Requires reduced administration hours		More than postal & interview	Compared to all methods
	Reduced data entry errors			Compared to all methods
	Can archive research in environmentally friendly way		Compared to all methods	Compared to all methods
Disadvantages	Lower response rate	Compared to interview	Compared to postal & interview	Compared to all methods
	Increased coverage error		Compared to all postal	Compared to postal
	No control over drop out/incomplete questionnaires	Compared to interview	Compared to interview	Compared to interview
	Increased risk of multiple responses from same person		Compared to postal	Compared to postal
	Bias introduced due to software incompatibility		Compared to postal & interview	Compared to postal & interview

Evidence summarised from[72,77,202,214,262,278,343,396,202,233,431,432,464,507]

5.3.4 Research design; Internet survey; world internet usage

It is clear from the previous sections that using web techniques in surveys has plenty of advantages. But the most important element for it to be successful is that people actually use the internet so the researcher can identify a group of people that can be representative of the population to be examined. This and the next sections aim to examine this matter.

The internet has a very recent history. In 1969, the ARPANET, the first network, was developed, and the internet was invented. In 1971, the use of email was introduced and a year later email lists were found. In 1990, the World Wide Web (WWW) was first used.[270] By 2010, nearly 29% of the world's population had access or used the internet.[315] North America has only the 5% of the world's population but 13.5% of the world's internet-user population. The percentage of internet users in Europe is 61.3% and in the European Union it is 71.5% (increased 6.5% in two years December 2009 - 2011). The overall growth of internet users around the world is 528% between 2000 – 2011.[315] In 2009, Greece showed an increase of 16.8% on information and communication usage compared to the same period in the previous year and home internet connection increased by 75%.[200] In the UK, 60% of internet users[339] and 64.5% in Greece[200] access the internet on a daily or almost daily basis with both countries showing an increase over previous years. Using the internet via a mobile device (mainly phone) increased to 45% (up by 5% in one year) in the UK. These figures show that among the three participating countries the number of users is high and growing fast.

Among the profile characteristics of internet users is that in the UK and USA more people with higher qualifications tend to use it. However, this is not the case in Greece where the highest usage is by young people who have recently finished high school and the lowest by those who have a Master's degree or above.[123] Lower household or individual income is related to lower internet use in the UK[200] but the reports for the USA are mixed.[85,454] Internet users in the UK connect to social networks (43%) and, the older the age group, the lower the percentage of people using the internet (Table

5.2).[339] This pattern is similar in the Greek population, however it is not similar in the USA population where the highest usage is by those aged 45-64 years.[454]

With regard to gender differences, in both the UK and Greece more men use the internet but this difference has been reducing.[200,339] Men are more likely to respond to web surveys[292] however, women are more likely to go online.[123] In the USA, slightly more women used the internet in 2009.[454] Despite internet users in the three participating countries having some small differences in their demographic profile characteristics, they use the internet for the same order of activities (Table 5.2).

A USA study found that those using the internet rate higher in self-rated health, memory and functional status.[85] Some evidence suggests that there is no significant difference between postal surveys and web surveys in regard to gender, age, income, education and country of residence of respondents.[150] Table 5.2 summarises the characteristics of internet users in the three countries of interest.

5.3.5 Research design; Internet survey; usage by people with SCI

So far it has been seen that internet usage is high in the general population. This study will recruit a group of people with a specific disability so it is essential to review internet usage by this particular group.

In 2006, one-third of people with disabilities used a computer at home while only just over a quarter had access to the internet from home. This could be due to technical accessibility problems as adaptive technology, which is often required by people with disabilities, is difficult to learn, expensive, and its development is behind that of Information Technology (IT).[123] However, different disabilities show different percentages of internet usage, therefore it is misleading to collapse all disabilities into one category.[123]

Table 5.2: General characteristics of internet users per country

	Internet access/ usage (%)	**Internet use by areas of residence** (%)	**Internet use by gender** M/F (%)	**Internet use by marital status** (%)	**Internet use by qualification** (%)	**Internet use by age group** (%)	**Internet use by income** (%)	**Internet activities** (%)
UK*	77	Wales: 67 London: 87	84/79	Single: 92 Married:81 Widowed: 32	Degree or higher: 97 No qualification: 45	16-24: 97 25-44: 93 45-54: 84 55-65: 72 65+: 32	>£41,600: 98 <£10,399: 69	Email: 90 General information: 75 Online news: 51 Social network: 43 Health information: 39 Looking for job: 26
USA**	77	West: 70 South: 65 Arizona: 79 Washington: 79	68/69	Single: 26 Married: 58.5 Other: 15.5	Degree or higher: 90 < highschool: 25	18-34: 69.1 35-44: 40.7 45-64: 76.9 65+: 40.8	<$50,000: 37[1] >$150,000: 12[1]	Email: 57 General information: 50 Online news: 38 Social network: 27 Looking for job: 29
Greece[3]	42	Greater Athens: 52 North: 40	58/49	Not reported	Master's & above: 4 Degree: 30 High school: 40 Junior high school: 12	16-19: 90 25-29: 72 35-39: 54 45-49: 40 55-59: 17 65-69: 3.3	Not reported	Email: 73 General information: 55 Online news: 50 Social network: 42 Health information: 19[2]

Studies used for references: *[339], **[3,200,454]; [1]Figure taken from 2008 statistics; [2]Figure taken from 2006 statistics

The percentage of internet and computer use by people with SCI is high. In the USA, in 2004, it was found that 67% owned a computer, 65% had home internet access and 65% used it daily.[127] Only a few years later these figures increased to 69% computer ownership, 94% of them had home internet access and 69% daily internet usage.[172] It is not only the percentage of people with SCI who use the internet that is essential but also their demographic profile characteristics. This examines if certain types or groups of people with SCI may be over- or under-represented. An equal percentage of people use and do not use assistive devices to connect to the internet (94% v 94.2%).[172] No significant differences were found for the use of the computer by gender or level of injury, but more males than females log on to use the internet.[172] There was a decrease in the use of the internet as age increased and both computers and internet were used more by white than black people and internet use significantly increased with education level[172] and income (higher income: more usage).[127] Presence of pain affected internet access (the less the pain, the higher the internet access).[127] People with SCI used the internet mainly for emailing followed by web surfing and chatting.[172,216]

Some 65% of people with SCI, compared to 77% of people from the general population,[454] use the internet. In addition, the level of injury does not affect internet use which means that people with tetraplegia and paraplegia would be expected to participate similarly in the survey. The fact that the presence of pain may negatively affect internet use was taken into account and actions were taken to make survey completion easier. The above provides a reasonable justification for the decision to use a web design to collect data from this population in the current project. Statistics about internet usage by people with SCI in the UK and Greece are not known, to the best of this author's knowledge, and the results of this survey may help to provide some interesting comparisons on this topic.

5.3.6 Research design; Survey; mixed-mode

It was mentioned earlier that the current survey uses a mixed mode method to collect data. This is when more than one method is used to collect data; for example, mixing internet with other types of survey. This approach gives an opportunity to compensate for the weaknesses of each mode but at an affordable cost.[98] As a method, it emerged because of the problems found in the other types of data collection methods[464] and it can help achieve a higher RR.[98] The mixed-mode survey may be the most applicable solution to study different populations or subgroups in comparative studies where people have different survey traditions.[98]

This last point was one of the main reasons for selecting mixed mode for this survey. Greece has lower internet usage, though increasing, (Section 5.3.4). Demousis et al[104] point out that reducing the gap in internet use between Greece and other EU countries may take some time. One indirect way to examine if people with disabilities in one country use the internet is to check how many disability-related websites exist and how many members they have. Only one such site was identified in Greece. This included people with all disabilities. It became obvious that additional methods had to be used to assist recruiting from Greece.

5.3.7 Research design; Survey; sources of error

In order to conduct a good study with reliable results, errors must be eliminated by addressing their sources in advance. The major sources of error in surveys result from 1) coverage, 2) sampling, 3) non-response and 4) measurement.[84] These errors will be described here but the steps taken to reduce them in this particular survey will be explained in the sections to follow.

Coverage error is when members of the defined population do not have a non-zero probability of being included in the sample to be drawn,[117] resulting in a mismatch

between the target[14] and frame[15] population.[84] If nearly all members of a population have internet access then coverage error becomes less of a problem.[117] In theory, the second type of error, sampling error, can happen because not all the members of the frame population are accessed.[84,117]

The next error, non-response, happens when people in the sample do not respond to the survey resulting in the possibility of them having given different answers if they had responded.[117] Another type of non-response error is when participants return the questionnaires but have not completed them properly. This can take two forms: 1) unit non-response when the whole questionnaire is not completed, and 2) item non-response when some questions are not answered.[431] This results in missing data which may create problems for the data analysis.

Although Sir John Sinclair in 1788 achieved a 100% RR following 28 reminders[97] (Section 5.3.2) this is a percentage that is hardly ever achievable. A RR of 75% reduces bias[347] but the RR can depend on the methods followed and the target population.[289] Online surveys have been found, on the one hand, to have lower RR than mail surveys[402] and, on the other hand, to have similar RR[289] or even higher.[77] Not many reports on online surveys RR exist but some reviews or meta-analyses give an average of 32% for an internet survey[185] and 40% for a web survey.[81] Postal survey studies on people with SCI have had RRs between 50% - 85%.[58,90,488,489] A few studies are available about internet usage by people with SCI however they did not follow an online (either email or web-based) recruiting approach, so the RR for this specific population for an online survey is not yet known.

Finally, the last type of error, measurement error, can result from giving inaccurate responses for various reasons like poor question wording, survey mode effect, comprehension problems and lack of motivation,[117] resulting in a deviation of the

[14] Target population is the set of people that the researcher wants to study or the population the researcher wants to make inferences about.[82] In this study it is people with iSCI.

[15] Frame population is "*a set of persons for whom enumeration can be made prior to the selection of the sample frame*".[178] In this study these are the centres used to recruit participants.

answer from the true value of the measure.[84] There are various techniques that can be used to reduce this type of error and those used in the current study will be addressed later.

All the above sources of error can occur in all types of survey design including web, mail, mixed-mode and interview surveys.[117] Ways of reducing them and increasing the RR are explored in detail using a model that describes each step of the process. Fan & Yan in 2010[143] reviewed the survey process and systematically summarised the literature taking into account theories related to survey methods described previously, (e.g. the tailored design method described by Dillman in 2000[117]), and illustrated the factors that can increase the RR when conducting a web survey in a model comprised of four steps.

5.4 Web survey process

Fan and Yan[143] identified a gap in the "theoretical model of the psychological process of web survey" and developed a model of the web process based on a conceptual framework. According to this model, the process of a survey in general, consists of three key elements; 1) the researchers, 2) the participants and 3) the tools. The process consists of four steps: 1) survey development, 2) survey delivery 3) survey completion and 4) survey return.[143]

The authors, Fan & Yan, gave permission for their model (Figure 5.1) to be used for the purposes of this thesis to describe the steps followed in this survey (Table 5.3). The current survey used three more actions that were not enclosed in the Fan & Yan model and they will be described in addition to the model; 1) piloting 2) ethics, and 3) confidentiality, anonymity and consent. They will be described under the first step of the survey process.

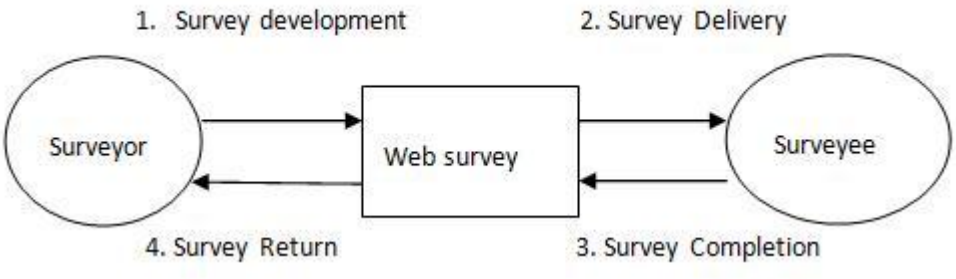

Figure 5.1: The web mail process as described by Fan & Yan.[143] (Figure used with permission by authors)

Table 5.3: Fan & Yan[143] survey process together with additional actions done in the survey

Key elements	1) Survey researcher (surveyors) 2) Survey participants (surveyees) 3) Survey tools (also called survey modes, e.g. mail, telephone and web)
Step 1; Survey development	1) Content of questionnaire 2) Presentation of questionnaire 3) Pilot* 4) Ethical Approval* 5) Confidentiality, anonymity and consent*
Step 2; (web) survey delivery	1) Sampling method 2) Contact delivery modes 3) Design of invitations 4) Use of pre-notifications and reminders 5) Incentives
Step 3; (web) survey completion	1) Participation in surveys 2) Participation decision
Step 4; (web) survey return	1) Survey software 2) Data safety

* Not described in the Fan & Yan process[143] but used in the current study.

5.5 Survey key element 1; Survey researchers (adapted from Fan & Yan[143])

The survey researchers are the surveyors who design and develop the web survey and put it on the web which is similar to those who develop a mail survey, print it out and use it.[143] This project had one main surveyor, the author of this thesis, who designed

the study. A number of collaborators participated in various stages of the project, including delivering of the survey (Table 5.4).

Table 5.4: Key element 1; Survey collaborators/volunteers

Overall project	Principal investigator (author of this thesis) Two thesis supervisors
Survey developing phase	Pilot phase; 10 people taking part Translation phase; 14 collaborators
Survey recruiting phase	Five major collaborators (including online sites/organisations and hospital units)

5.5.1 Survey collaborators/volunteers; UK arm

The Spinal Injury Association (SIA) greatly assisted in the study. Members of the SIA team participated by assisting in the development of the web-based survey, the pilot and the recruiting phases in the UK.

5.5.2 Survey collaborators/volunteers; USA arm

The National Spinal Cord Injury Association (NSCIA) approved of this study being advertised on their website. Members of the association placed the invitation for the study on the appropriate section of their website.

5.5.3 Survey collaborators/volunteers; Greek arm

The main collaborators in recruiting from Greece participated in the mail survey. There was one medical visitor who worked as a local co-ordinator assisting in the phases of piloting and recruiting by contacting other collaborators and distributing paper questionnaires either to them or directly to eligible participants. Two local hospitals and one medical centre were used for recruiting. They were the General Hospital of the city of Kavala, a medical centre in Chrysoupoli based in the city of Kavala and the General Hospital of Papageorgiou in the city of Thessaloniki.

Kavala is located in the East Macedonia region in Greece has a municipality population of 70,360 and a regional population of 124,480 making it the fifth largest city in Greece outside the Attiki region (which includes Athens).[199] Thessaloniki is located in the area of Central Macedonia in Greece; it has a municipality population of 322,240 and a regional population of 1,104,460 making it the second largest city in Greece after Athens.[199]

The team at the General Hospital in the city of Kavala was led by the director of the "Patient flow" office who assisted in obtaining the necessary hospital approval and identifying eligible participants via the central computer list. One medical doctor based at the Medical centre of Chrysoupoli was in close contact with the local co-ordinator of the study and distributed paper questionnaires to eligible participants who visited the centre. At the General Hospital of Papageorgiou in the city of Thessaloniki the study was approved and access to patients' medical records and the computer for a Neurosurgery clinic was permitted. The local team was lead by one medical doctor who assisted in obtaining the necessary approvals and also discussed the eligibility of some participants whose available information was partial.

5.6 Survey key element 2; Survey participants (adapted from Fan & Yan[143])

To take part in the study, participants had to meet the following criteria:

Inclusion criteria

1. Adults, above the age of 18 years, who live in the UK, USA, or Greece;
2. They must have an incomplete spinal cord injury.

Exclusion criteria

1. People younger than 18 years of age;
2. People who do not have SCI;
3. People with complete SCI;

4. People who do not live in the UK, USA, or Greece;
5. People who do not speak English or Greek.

5.6.1 Sample size calculation

A statistician, independent to the study, conducted the sample size calculation required for this project. Information from the paper by Kennedy et al,[240] which reported 14% of pain in the lumbosacral area of the SCI sample, was used. The sample calculation assumed that the percentage of LBP was 14% and with 95% CI either side of the estimate (9%, 19%), a total of 185 participants for all three countries were needed to answer the questionnaire.

5.7 Survey key element 3; Survey tools (adapted from Fan & Yan[143])

The third key element in a survey study, according to Fan & Yan[143] is the tools used for a survey. Those used in the current study were postal mail and the web questionnaires.

Eligible participants from all three study arms were offered the option of requesting a paper format questionnaire which they would return by post. Recruiting from Greece greatly depended on the mail survey and for this reason a return account using a pre-paid envelope system was set up with the local post office. For web data collection SurveyMonkey©[434] was used. This is a web-based online host which collects data centrally and access to it is by subscription. More details on how this tool was used are explained later.

5.8 Survey steps; Step 1; Survey development (adapted from Fan & Yan[143])

The first step of the process is about developing the questionnaire and putting it on the web, and as the authors[143] comment, it is a similar stage to creating and printing a

paper questionnaire. This step includes two elements known to affect RR: 1) content, and 2) presentation.[143]

5.8.1 Survey steps; Survey development; content of questionnaire

The content of the questionnaire is affected by three factors: 1) official sponsorship, 2) topic of study and 3) length of survey.[143]

5.8.1.1 Official sponsorship

Sponsorship can motivate eligible participants to complete a survey[342] and affects both mail and web surveys.[143] This particular study was sponsored by the School of Health Sciences and Social Care (SHSSC) at Brunel University, London, UK. In addition, the study was partially funded by the Engineering and Physical Sciences Research Council (EPSRC) (as part of further funding for the PhD) and a small grant from the Graduate School of Brunel University. Support for the study by some well known national associations or organisations in each country was obtained.

5.8.1.2 Topic of survey

If the topic of the project is of interest to the people surveyed then this has a positive effect on RR[194] and even long and complex questionnaires can be completed.[343] Aiming to identify groups of people who would be interested in the study, it was advertised on SCI-related websites.

5.8.1.3 Length of questionnaire

The last factor to affect content of the questionnaire is its length. It has been reported that long questionnaires can result in people dropping out of the survey before completing it.[25] However, other studies conclude that the length of the questionnaire is not associated with a reduced RR,[81,408] suggesting that maybe the negative effect of the length of the questionnaire on the RR has been overestimated.[408]

The questionnaire for this project was 24 pages long in the paper format and the same number of questions was laid out over 20 pages on the web format, thus it was a long questionnaire. Taking into account the fact that the target population would have

possible physical problems which could limit the time they could spend completing the questionnaire, participants were encouraged to take breaks. The web survey was set up appropriately to enable continuation of completing the questionnaire if the participant had one or more breaks.

5.8.2 Survey steps; Step 1; survey development; presentation of questionnaire

The presentation of the questionnaire is the second element of step 1 and it is affected by 1) question writing, 2) question wording and 3) visual display.[143] When a questionnaire is easy to understand, it motivates the respondents to fill it in and minimises errors.[84] The questionnaire should aim to be conservative but pleasant, attractive, consistent and keeping open-ended questions to minimum.[343]

Harzing[194] conducted an international study in 22 countries sending questionnaires written in English. They found that English language capability negatively affected the RR and suggested that in cross-national studies the questionnaires should be translated for the non-English speaking respondents despite their level of English. They emphasised that translation may further motivate the respondent to complete the survey by appreciating the fact that the researcher translated the questionnaire.[194]

Part of the survey development and related to the presentation of the questionnaire were the stages of piloting (or pretesting), obtaining ethical approval and securing confidentiality, anonymity and consent. These stages are not discussed in the Fan & Yan process[143] however they are essential to a survey, and for this reason are presented here. As they were part of step 1 they will be discussed below before moving on to reviewing step 2.

5.8.2.1 Question wording and ordering

Question wording can affect responses and introduce bias especially when they are complex, leading, have double negatives or other difficulties.[36] People may interpret words differently therefore use of short, simple, specific and familiar words is

advised.[36] Complex questions should be broken up into shorter ones[36] and long questions can cause comprehension difficulty.[229]

Consideration given to the order of the questions is pointed out in the literature and the "funnel" approach, which starts off with broader questions and then narrows down to more specific ones, is quoted.[343] Filter questions can be used to exclude people from questions that are irrelevant to them.[343]

The current questionnaire included three validated measures where question wording and ordering is believed to have been taken into account when developing the measures. The final part of the questionnaire consisted of questions selected by the PI in order to collect demographic and other information of interest. Questions were ordered using the "funnel" approach when possible. Filter questions were used in many cases to help reduce time spent with non-applicable questions.

5.8.2.2 Visual display

The question of display may be more difficult to standardise in a web survey than in a printed survey as the format of the questions may be affected by different internet browsers and the screen of the device used.[396] Usage of appropriate programmes may eliminate this problem.[25,117] Visual display is improved by drop-down and scrolling questions[117] though this has been debated.[357] The size of the text can impact visual display and Arial 12 pt. font is recommended.[25]

To decide on the visual display of the survey the above recommendations along with the guidelines of the Survey Monkey© software[434] were taken into account. The survey was previewed on the major web browsers and using different versions of Windows to ensure the questionnaire looked the same on each browser.

5.8.2.3 Language of questionnaire

The last factor to affect presentation of the questionnaire is its language. The official language in the UK and USA is English, however, in Greece the official language is Greek and 99% of the country's population report it as their native language.[138] Half of the Greek population (48%) speak a good level of English, however the vast majority of

them (89%) do not use it daily.[138] Taking into account the study of Harzing[194] and the affect of language on RR (Section 5.8.2), it was decided that Greeks should receive the survey in Greek making it easier to understand and reduce errors. The translation procedure was explained in Chapter 4.

5.8.3 Survey steps; Step 1; survey development; pilot phase

Fan & Yan[143] did not discuss piloting in detail but said that it is essential during the first step of survey development before the questionnaire is distributed to potential respondents. Piloting improves the wording and order of the questions[343] and identifies questions that need to be eliminated or revised.[430] The people who pilot the survey should have similar characteristics to those who will eventually respond to it.[343]

The three standardised measures used in the survey were assumed to be pilot tested by their developers including those that had already been translated and validated into Greek. The final part of the current survey collecting socio-demographic information was piloted by both English and Greek speaking people. The complete questionnaire was also piloted to examine the time needed to complete it.

The pilot procedure was divided into five stages (Table 5.5) including a pre-pilot and a translation stage. At stage 2, some of the people with SCI who piloted the survey were members of the SIA with experience of SCI studies and their feedback was of great importance. Stage 3 included translation into the Greek language (Chapter 4). At stage 4, the Greek part of the questionnaire was piloted by people with SCI and lay members and appropriate corrections were made. Finally, at stage 5, final corrections were made before sending the survey out to participants.

Table 5.5: Stages of pilot of the survey

Stage 1; Pre-pilot	SHSSC Ethics Committee reviews study for approval and offers valuable suggestions on the survey design and questions.
Stage 2; Pilot English version	Survey is piloted online and on paper by a group of people with SCI, members of SIA, and by lay members. Discussions when appropriate followed.
Stage 3; Translation	Following corrections of the English version the survey is translated into Greek.
Stage 4; Pilot of Greek version	Survey is piloted online and on paper by a group of people with SCI and by lay members. Discussions when appropriate followed.
Stage 5; Finalising	The changes to the Greek version are translated into English. Both versions are discussed with lay members or health professionals of English and Greek origin. Changes are made as appropriate to surveys for each arm of the study. Researcher checks for typos and errors.

Abbreviations: SHSSC, School of Health Science and Social Care; SCI, Spinal Cord Injury; SIA, Spinal Injury Association.

5.8.4 Survey steps; Step 1; survey development; ethical approval

Ethics has got its roots well back in ancient Greece. The Hippocratic Oath (written in the 5th century BC) says "*do no harm or injustice to them*" (the patients), and "*whatever I see or hear in the lives of my patients...I will keep secret*".[455] Aristotle (384 BC – 322 BC) wrote over 20 books where he discussed the morality and ethics of social living.[14] The modern form of ethical guidelines started by the Nuremberg code in 1949 and the first official guidelines were introduced in mid 1970s.[141] Online research could go beyond institutional borders and national boundaries of specific ethics requirements as people from any geographical area could log online.[141] The Association of Internet Researchers (AoIR) developed some guidelines that help to conduct online research taking into account the diversity of cultures.[135]

A number of ethical issues are raised in the planning of a study[384] and the effectiveness of using the internet to conduct international studies may expose researchers to legal liabilities that are different to those of their own countries.[72] Therefore it is essential for the study methodology to be reviewed by a team of experts. The methodology of this survey was reviewed by SHSSC Research Ethics Committee of Brunel University

and ethical approval was granted (Appendix 2). In addition, local approvals to conduct the study were given by the research and development bodies (hospital management board) of the hospitals which took part.

5.8.5 Survey steps; Step 1; survey development; confidentiality, anonymity and consent

The information reviewed (questionnaire data) must be treated with confidentiality which also increases the RR.[343] Confidentiality and anonymity were secured in this study by implementing the following:

1) Collaborations and approvals were secured prior to commencing recruiting;
2) The questionnaires were anonymous, however the participants had the option to provide their name, address and contact details;
3) In the case of the returned online questionnaires, the Internet Protocol (IP) address of the computer was de-activated. An IP address is the mark of each computer, which could lead to identifying the respondent and therefore it could be a potential violation to consent and anonymity if the respondent is not informed about it.[233] By de-activating the IP address anonymity was secured. When entering data into the computer each participant was coded using a pin number;
4) Paper data were kept in locked cabinets accessible only by the PI who withheld the right to show detailed data to the PhD supervisors. Computers used for this project were password protected;
5) The local collaborators, who assisted in recruiting, were not aware of the participants' details who returned the questionnaires as they used the prepaid addressed envelopes to return them directly to the PI or left the completed questionnaires in sealed envelopes for collection by the local co-ordinator. In the case of web questionnaires the collaborators had no access to the online database.

Eligible participants must be fully informed of the study, understand it and be able to consent.[141,214] Guidelines about information sheets exist[327] and they were read to help design the current information sheets. For online research permission of the site owner, posting the information sheet on the message board and reading the site's regulations are recommended.[214]

The participants in both the paper and the web version of the questionnaire were asked if they wanted to take part in the study. By providing completed questionnaires they automatically consented to participate. The participant should be given the right to withdraw from participation,[289] and this option was given provided that their questionnaires were not returned anonymously.

5.9 Questionnaire components

Before moving on to describe step 2, which deals with survey delivery, a description of the measures and questions included in the questionnaire is provided. The questionnaire "package" was divided into four following parts.

5.9.1 Survey questionnaire; Part 1 - examining pain; The Short Form McGill pain questionnaire

A number of pain assessment scales were looked at in order to decide which one was the most appropriate to use. Three were selected for consideration; 1) the multidimensional pain inventory (MPI), 2) the Chronic Pain Grade Questionnaire (CPGQ) and 3) the McGill Pain Questionnaire (MPQ).

The reason for excluding the MPI was that despite it being a reasonable tool to measure the impact of pain in people with SCI, it has been suggested that due to the differences in activity based on the level of injury the MPI may not necessarily reflect impairment from pain.[485]

The CPGQ has been used in SCI[58,406,451] and despite its good properties[414,472] it was excluded because it has not been used as extensively as the MPQ. Another important reason for excluding it was that it did not exist in the Greek language.

The MPQ provides quantitative measures of clinical pain and examines three dimensions of pain; 1) the affective, which is how the respondent feels at that moment, 2) the sensory, which is the sensations the person has at that moment and 3) the evaluative, which describes the subjective overall intensity of the total pain experience.[305] It takes 15-20 minutes to administer.[304] Four types of data can be acquired from it:

1) Pain rating index based on the patient's mean scale values (S-PRI), which is the sum total of the scale values of the chosen words in a category or all categories;
2) Pain rating index based on the rank values of the words (P-PRI), where the values of the chosen words are added to give a total score for each or all categories;
3) The number of words chosen;
4) The present pain intensity (PPI), which is the number-word combination chosen that indicates the overall intensity at the time the questionnaire is administered.

The MPQ was found to be too long and in 1987 Melzack[303] developed a short-form (SF-MPQ) consisting of 15 descriptors (11 sensory and 4 affective) rated on a scale 0 to 3 (none to severe), includes the PPI and a VAS and provides information on the sensory, affective and overall intensity of pain and takes two minutes to complete.[303] Both the MPQ and the SF-MPQ have been used in studies to assess self-reported pain in adults with SCI.[31,58,380,381,451]

Concerns have been raised about the true number of dimensions included in the MPQ as some studies found four or more factors when using factor analysis.[305] But, support for the original model was given and with the exception of the descriptor "gnawing", the factorial validity of the English version of SF-MPQ was confirmed.[502] The discriminant validity of the measure has been questioned as Turk et al[448] found that

the inter-correlations in the PRI were too high thus not allowing adequate discriminant validity and proposed using the total score of the PRI. However, Melzack[305] claimed that the high inter-correlations among the variables do not essentially mean that there is lack of discriminant abilities and the validity of the scale has been shown in other studies. Another difficulty with the MPQ is that high affect scores can reduce its discriminant abilities, however Melzack[305] who does not doubt this problem, claims that MPQ still maintains good discriminant ability even in cases of high levels of anxiety. It has also been mentioned that the MPQ is less sensitive to clinical change compared to the VAS[398] and also that using only verbal descriptors to distinguish pain types in SCI is limited.[367]

The MPQ developers have not, though, claimed it to be the perfect tool in assessing pain[305] but its psychometric properties have been studied by others.[82,423,502] The SF-MPQ has also been found to be a good tool as a predictor of the result.[474] SF-MPQ has been translated into Greek by Georgoulis et al[166] who studied people with chronic spinal and osteoarthritic MSKP. The questionnaire was found to have an internal consistency of Cronbach's Alpha α=0.71, to be reliable and sensitive to change following therapy for people with chronic pain including LBP[165] or patients with cancer.[324]

After the design and the onset of the current study an initial validation of a revised version of the SF-MPQ was developed. Its objective was to better assess and distinguish between neuropathic and non-neuropathic pain, it uses seven more verbal descriptors and it replaces the four-point rating scale to a 0-10 NRS.[129] Thus, the revised version of SF-MPQ, if used in future studies may become a more appropriate tool for the assessment of pain.

In addition to the SF-MPQ, the body chart, which is used in the full MPQ was used. A body chart or pain drawing or body map is used extensively in the literature[90, 484,487,488] or clinics and the respondents mark the location of their pain. The use of the body chart aims to collect information on the pain extent.

5.9.2 Survey questionnaire; Part 2 - examining quality of life; The EQ-5D questionnaire

A number of measures have been developed aiming to measure QoL by summarising individuals' judgements on their experiences of health and illness.[62] These measures do not aim to measure the disease or conditions particularly but their impact on QoL.[62] Measuring HRQoL enables identifying such problems with the aim of improving them. Sometimes QoL is measured by health professionals but QoL is a subjective evaluation, thus measurement needs to be done by the person themselves. Slevin et al[411] said that doctors did not adequately evaluate the patient's QoL.

The QoL scales that were considered for inclusion were 1) the WHO QoL – BREF (WHOQOL-BREF), 2) the SF-36 and SF-12, and the 3) EQ-5D.

The WHOQOL-BREF has been used in studying people with SCI and has acceptable validity[226] and the long version (WHOQOL-100) has been translated into Greek.[170] However, the WHOQOL-BREF could not be found in the Greek language, and even if it existed it consists of 26 questions which was too long for a single measure to be included in this study. The SF-36 and SF-12 are widely to assess for health-related QoL. However barriers had been reported when using them in SCI which led to some modifications of the SF-36 to enable use in SCI research with good construct validity.[438] Despite the original SF-36 being available in the Greek language, the measure was found to be much longer than the EQ-5D to be included in the survey.

The EQ-5D is a widely used measure to assess health status[41] with universal application.[505] It measures mobility, self-care, usual activities, pain/discomfort and anxiety/depression.[341] It is a simple, short and easy to administer, generic, self-completed measure of health status that has been used in various studies,[143] has no complicated tasks and has been used by people with SCI.[294,302] The EQ-5D has been translated into Greek and returned good validity results when studied on the general population.[247] When it is compared to another HRQoL measure on the Greek population it was found to be equally acceptable.[506] The version selected for use in the current study was the 3-level one. A 5-level EQ-5D version has been created but it needs further development[227,359] and thus not chosen for use here.

Suarez-Almazor et al[429] evaluated the discriminant abilities over time for a number of health status measurements, including the EQ-5D, in patients with LBP. They found that even though the EQ-VAS, which is included in the EQ-5D, was one of the least stable measures it could discriminate better among those patients who improved and those who got worse than most of the SF-36 subscales.[429] There have been some concerns in the literature about the ability of the mobility dimension of the EQ-5D to properly assess and discriminate individuals' levels of disability, particularly in SCI.[108,168] The mobility dimension refers to the difficulties with "walking about" which people with iSCI may be able to maintain, those with a complete injury probably would not.[108] But, wheelchair users may consider "walking about" similar to "getting about" so this may not be such a great problem.[168] In the present study only people with iSCI participated thus problems with the mobility dimension should not be expected (see Appendix 2 for this measure).

The current study has been registered with the EuroQol Group[140] who provided all relevant documentation for both the English and Greek versions.

5.9.3 Survey questionnaire; Part 3 - examining function; The Spinal Cord Independence Measure (SCIM) questionnaire

Among the scales used to examine function those that were considered for inclusion were 1) the functional independence measure (FIM) and, 2) the SCIM. The FIM has been used to assess function in many conditions including SCI,[237] however it has been said that a total FIM score in the SCI population may be misleading as some of the domains (i.e. cognitive) have been reported to be inappropriate for SCI.[184] In comparison with SCIM, the FIM was found to be less reliable to change for people with spinal cord lesions.[68] FIM was not found in Greek either, similar to SCIM.

SCIM is the only "*comprehensive ability rating scale that has been designed specifically for patients with spinal cord lesions*".[65] In SCI it is necessary to use a condition-specific measure even with adequate measurement properties.[96] SCIM assesses function covering three principal areas:[68]

1) Self-care including tasks of feeding, bathing, dressing, and grooming;

2) Respiration and sphincter management including tasks of respiration, bladder & bowel management, and use of a toilet;

3) Mobility, which is divided into tasks in a) room and toilet, and b) tasks indoors and outdoors (see Appendix 2 for SCIM).

The original SCIM had high inter-rater agreement correlation coefficients ranging from 0.91-0.99[68] but it was revised (SCIM II) and the new version showed better correlation coefficients between the two raters in total scores (r=0.99).[67] Compared to the original version it was more reliable in the category of self-care (80-99% vs 75-87%) making it a valid and highly reproducible measure of daily function for people with spinal cord lesions.[67] A large population study using SCIM II confirmed its validity and reliability and concluded that despite some flaws it is suitable and recommended for use.[224] SCIM was designed as an observational measure and seems to show better properties when used for assessment by a multidisciplinary (MTD) team compared to a single rater.[66]

Conducting a systematic review, Dawson et al[96] noticed that the measures used to assess function in SCI rely on observation, thus on the assessor's perspective and do not represent the patient's perspective. The authors expanded on the debate about whether more accurate data is collected by observation (as claimed by Itzkovich et al[223]) or by self-report and mentioned that when SCIM was assessed by interview the differences between patients' ratings and observers appeared insignificant.

Indeed, SCIM was tested for assessment via interview[223] where the interviewers had no specific training in using it and the correlation between the total scores of the interviewers was high (r=0.903). When comparing the results of the two interviewers with those of the observers the correlations were also high, ranging from r=0.69-0.96.[223] The only statistical difference was between one interviewer and the observers on the mobility subscale and the other interviewer and the observers on the self-care subscale.[223] They concluded that SCIM could also be reliable by interview, however these findings might be less accurate than those with observation.

Studies on SCIM led to the development of the SCIM III version which consists of three complementary subscales including 6, 4, and 9 items, respectively. Each item

represents a daily task and is graded on an increased difficulty therefore demanding a higher patient ability. Each item consists of 2-9 grades and the higher the grade the better the patient's performance/independence. The scores range from 0-20 for "self-care", 0-40 for "respiration and sphincter management", and 0-40 for "mobility", totalling 0-100 for the three subscales. The mobility subscale has two subscales; "room and toilet" and "indoors and outdoors, on even surface".[65]

SCIM III has an intraclass correlation coefficient (ICC) of above 0.94 for the total SCIM and for all subscales. It has improved inter-rater reliability compared to version II, internal Cronbach's α consistency for the overall SCIM III α=0.847 and α=0.849 (first and second raters). Validity of scale when compared to FIM was r=0.79. SCIM III was tested by observing more than 400 people in 13 centres in six countries and it showed good validity and better responsiveness to respiration and sphincter management for mobility indoors and outdoors subscales.[65,222] SCIM III was suitable for cross-cultural research[65,222] (Appendix 2).

For pragmatic reasons and because of the methodology of the present study, it was impossible to use SCIM III by observation or interview. The only way to use it was by respondent self-report. Using SCIM III via this method should give information on how this assessment works under this condition.

5.9.4 Survey questionnaire; Part 4 - socio-demographic profile and other related information

The final part of the questionnaire consisted of 58 questions developed specifically for this study to collect socio-demographic data and other information of interest and was divided into four sections.

The first section, labelled "Questions about you" consisted of 22 questions collecting demographic profile information. The second section labelled "Questions about your pain in general" consisted of 15 questions related to the respondent's pain in general since the time of injury and type of treatment received. The third section, labelled "Questions about your LBP" consisted of 15 questions similar to the second section but

about LBP. The final section, labelled "Final questions about yourself" consisted of six questions investigating whether the respondents completed the questionnaire on their own (Appendix 2).

This part of the questionnaire included factual questions starting with classification questions related to the general demographic characteristics of the population (e.g. age, sex and education).[343] These were mainly closed questions which are easier and faster to complete but may be considered not as flexible which can lead to loss of rapport.[343] To allow more flexibility, in many cases the closed questions were followed by an open-ended alternative (i.e. "other – please state" option) which provides a compromise[118] and aims to collect additional information. The questions were on nominal, ordinal (including ranking) and continuous levels of measurement. Filter (skip) questions were added and respondents completing the paper version were directed to the appropriate skip question but those completing it online were automatically taken to the relevant questions. Omitting questions can produce problems with the questionnaire,[396] therefore a logical technical solution was set up asking respondents to complete the questions regarded to be essential for the survey. This was a benefit of the web survey over the paper survey.

5.10 Survey steps; Step 2; the survey delivery (adapted from Fan & Yan[143])

Moving on to the next step of the process (Table 5.3),[143] the sampling method is decided, participants are contacted and the web survey is delivered to them, similar to the mail survey being distributed to the respondents. The elements that can affect RR in this step are five; 1) sampling method, 2) contact delivery mode, 3) design of invitations, 4) use of pre-notifications and reminders and 5) incentives. Each of these elements is discussed below.

5.10.1 Survey steps; Step 2; survey delivery; sampling

Population is the whole group for which generalisability results will be made[431] and in this case the target population is adults with iSCI. The sampling frame is the list of units of the population from which the target sample is drawn[36] and here these are the online and offline centres used to recruit participants.

The most commonly used sampling recruiting technique on the internet is to post the study on websites or newsgroups asking people to participate.[202] It is understood that this type of sampling creates problems with the RR as it cannot properly be measured,[202] however as there is currently no central registry as, for example, there is the telephone book which can be used for telephone research, this problem is more often encountered. Sending emails to the eligible participants may give an approximation to the sampling frame.[202]

For the purpose of this study a combination of sampling recruiting techniques were used. Primarily, convenience sampling was used for the web survey. This means that the study was posted on communities, forums, online websites[431] and people with iSCI were invited to participate. A second type of sampling used, which also falls into the category of convenience sampling, was judgement sampling. This is when the researcher selects the sample from the online community.[156] This was done subjectively in two ways; 1) in cases where the website was generic and included people with all disabilities, then the SCI-related forums were identified and the study was posted on them and, 2) by looking at people's registrations profiles (when freely available to other members to view) and those believed to match the study's criteria were invited to participate via an email or a message. A third sampling technique used for online recruiting was the saturation method. This is when all the members of the frame have an email address and an email can be sent to them thus this technique has no coverage error.[431] However, only one website was found to offer this option.

Finally, the sampling frame for the mail survey was based on convenience. No register of people with SCI existed in Greece, online or offline, to the author's knowledge, at

the time of recruiting. The hospitals and the medical centre were selected because the PI had access and collaborations that could be established.

For each arm of the study, the sampling procedure is described below.

5.10.1.1 Survey steps; Step 2; survey delivery; sampling; UK arm

The study was published directly by the SIA on their electronic-clips bulletin, which had a membership list of 2,500 people and it was on the front page news for a few weeks. The study was also published in the Association's "Forward" magazine and put on the message board. At that time there were 1,941 registered members online.

Two further, UK-based online sites for people with SCI, were identified. Combining the sites at that time, there were more than 6,800 registered members. The study was advertised on some forums of these websites.

5.10.1.2 Survey steps; Step 2; survey delivery; sampling; USA arm

NSCIA had 1,060 subscribed members at the time on their online forum but more than 24,000 members belonged to NSCIA. Nine further USA-based online sites were identified and posts were put on various forums. For six of them the given total number of registered members was more than 35,500, however one of the sites (with 30,000 registered members) included people with various disabilities (some 425 were believed to possibly fit the study's criteria).

5.10.1.3 Survey steps; Step 2; survey delivery; sampling; Greek arm

"Disability Now" is a non-profit, non-governmental organisation, mainly managed by people with severe disabilities. It was the only organisation related to disability to have an extensive online site consisting of discussion boards and forums. The site had more than 1,000 registered members with various disabilities at that time. An advert promoting the study was approved and placed on the forum.

At the General Hospital of Kavala the general records of all patients that had been seen in the hospital since 01/05/1996 were available. A total of 34 keywords were used to search the hospital's central computer and 615 results were returned. These

were screened in more detail and 122 people were found to have SCI. Only 14 cases were confirmed iSCI, however a total of 72 letters were sent out because the information available suggested some of these possibly had an iSCI. For the remainder, eligibility remained unclear. At the Medical centre in Chrysoupoli, Kavala, access to the records was not requested, therefore it is not known how many people were on the database of this centre.

Finally, at the General Hospital of Papageorgiou, in Thessaloniki, access was given to the records of the clinic of Neurosurgery. The registration books of people entering the clinic were reviewed manually for the years 10/09/2002 – 03/12/2008[16]. A total number of 5,491 people were seen at the clinic, of whom 128 were selected as eligible to participate and were further reviewed. There was a clear diagnosis of iSCI for only 7 people reported in the medical registration books, however 28 letters were sent out to people considered to fit the study's criteria. For the remainder, the diagnosis was not clear and they were excluded.

Table 5.6 below presents an overview of the sampling frame, the contacts made and an estimation of the people identified in each arm of the study but, as previously mentioned, an accurate RR is not feasible for online research. One of the problems encountered in this study and which made determination of the RR difficult was that not all members registered with an online site had SCI themselves but were relatives or friends of a person with SCI. They were sent an email and asked to forward the invitation to the person with SCI but it can only be assumed that this was indeed done.

Another problem was that in many cases it was unclear if the SCI was complete or incomplete, however emails were sent anyway and people were asked to participate only if they had an incomplete injury. A third problem was that people could be registered with more than one site, thus not accurately reflecting the number of individuals with SCI. In those cases where people had no description on their profile at

[16] Excluded periods not registered in the books were: 25/12/02 - 02/01/03, 01/01/04, 01/01/05 - 2/01/05, 31/12/05, 29/12/06 - 31/12/06.

all (which was very common) no invitation was sent and people with SCI may have been missed out.

A further problem was that even if a site was based in the USA, for example, people from other countries could register, thus creating difficulties in estimating the number of people with SCI in a single country. Finally, in most cases no email address was available and contact was made by sending a private message. Private messages were held "online" by the web-creator (host site) and the account holders were automatically informed via the host site about the presence of a private message available to them online. They then had to log onto the site to read the message. There is no way of knowing how many emails were indeed delivered and how many people actually logged onto the site to read the private messages sent by the PI of this study.

Screening people's profiles for eligibility was more time-consuming. However, it probably enhanced the RR by targeting people who fitted the inclusion criteria and by sending personalised invitations.

5.10.2 Survey steps; Step 2; survey delivery; contact delivery mode

The next element in step 2 is the contact delivery mode (Table 5.3). This is a message or an email invitation sent to eligible respondents informing them of the imminent arrival of the survey or giving them the hyperlink to the survey.[143] As discussed in Section 5.10.1, this was one of the recruiting techniques used.

Table 5.6: Overview of sampling frame, contacts, and responses per study arm

	UK Arm/sites	USA Arm/sites	Greek Arm/sites
Collaborators and hosts	SIA and 2 online hosts	NSCIA and 9 online hosts	Disability Now online host, 2 hospitals, 1 Medical centre
Known number of registered members at the time	Online: 4,441 Registered with paper magazine: 7,000	Around 30,000 registered with SCI sites only	Online: Over 1,000 but with various disabilities Hospitals (people with probable SCI): 250. Information from medical centre not known.
Profiles looked at	1,406	24,344	Online:1,000 Names screened at computer/books:
Confirmed incomplete SCI via self-report or in hospital records	60 living in UK and another 12 living in USA	288 living in USA, 7 in UK, 22 in Canada and 1 in Greece	Online: 7 Via hospitals: 21 Information from medical centre not known.
Total personalised emails sent out and letters posted	112 (18 from USA & 12 were confirmed relatives or partners of a person with SCI)	1209 (including 25 known relatives or partners of a person with SCI, 33 in UK, 22 in Canada and 1 in Greece	Online: 29 (including 3 relatives or partners of a person with SCI) Hospital: 100 Given by Dr by hand: 40
Number of people started survey online	344	132	37
Number of people completed survey online	149	69	12
% of online completeness of survey	43.3%	52.3%	32.4%
Number of returned paper questionnaires	1	3	Via hospital: 8 Via Medical Centre: 38

5.10.4 Survey steps; Step 2; survey delivery; pre-notifications and reminders

Using pre-notification slightly increases the RR.[81] In the current survey a type of pre-notification was made by posting an introduction and brief presentation of the study on the most popular forums of each online site.

Reminders are found to increase RR in surveys. [236,343] In this project, in general, no reminders or follow-ups were sent out. The only exception was the re-advertising of the study on the SIA front page. It is worth noting that of those people who viewed the three arms of the study online, the UK arm had the highest survey completeness rate and re-advertising may have influenced this. The reason for not sending reminders and follow-ups was pragmatic as the required sample size had been achieved.

5.10.5 Survey steps; Step 2; survey delivery; incentives

The final element in step 2 is incentives. These can be either monetary or non-monetary. In this study no incentives were offered and therefore this will not be further discussed.

5.11 Survey steps; Step 3; survey completion (adapted from Fan & Yan[143])

The third step for a web survey is when the respondents receive the invitation to participate, log into the study, complete it and submit it, similar to receiving the mail survey, completing it and posting it back. The factors that are important at this stage and may affect RR are 1) prior participation in the survey, and 2) decision to participate.[143] One could claim that prior participation in surveys is directly linked to the decision to participate in a survey thus these factors are discussed together.

5.11.1 Survey steps; Step 3; survey completion; prior participation in surveys and decision to participate

The decision to participate in a survey can be affected by elements related to 1) the society, 2) the respondent and 3) the design of the survey.[143]

People may decide to participate (or not) because they are interested in the topic,[180] they want to present themselves as helpful,[431] for social reasons[143] or they find the

topic sensitive.[194] A society may suffer from questionnaire fatigue making potential participants less likely to respond compared to other societies where questionnaires are not so commonplace.[143,194,195] Finally, the design of the survey can affect the decision to participate. Zhang[507] noticed that, when given the option, 20% of people chose to complete a postal survey over the web format and proposed offering alternative ways of distributing and collecting a survey. In this survey, this option was offered, although not many people requested a paper survey.

Another factor affecting the decision to participate is the geographical distance between the surveyor and the surveyed.[142,143,194,195] One technique for overcoming cultural and geographical distance is to mail (postal) questionnaires from the countries to be posted to and to have local collaborators.[194] Both these techniques were followed when possible in this survey.

5.12 Survey steps; Step 4; survey return (adapted from Fan & Yan[143])

The final step in the survey process is the return of the questionnaire (Table 5.3) which for a web survey is when the researcher downloads the collected data from the website to the computer for analysis similar to the process of entering data from a mail survey into the computer.[143] This process can be influenced by the 1) survey software and 2) data safety.

5.12.1 Survey steps; Step 4; survey return; survey software

Hundreds of survey software products are available in the market and a list can be found in http://www.websm.org.[465] The advantages of having such a programme include 1) that data is stored in a central location, 2) the survey is always up-to-date and 3) a backup is usually available if needed.[233]

For the current study a professional subscription with Survey Monkey©[434] was taken out. This gave full access to the benefits of the software licence including unlimited

responses on the surveys and fast and helpful customer support. The questionnaire could be designed in both English and Greek, data could be downloaded in Excel spreadsheets and transferred into the statistical package SPSS.

5.12.2 Survey steps; Step 4; survey return; data safety

Even though data safety in web surveys is a concern, the risk may not be higher than in non web surveys and there are ways to reduce it.[143] In the UK, 87% of internet users expressed strong or mild concern with abuse of personal information.[339] Security is strengthened by having the appropriate anti-virus programmes and firewalls. Access to the computer should be via a password.[289] Appropriate security measures were in place in this study.

In conclusion, this chapter has so far explained in detail the methods used in this survey discussing, at the same time, the methodology behind them. The next sections of this chapter will discuss the methodology and methods employed to conduct the statistical analysis of the survey.

5.13 Methodology of data analysis

5.13.1 Data analysis; Preparation for analysis

A “code book” was created which included rules of coding taking into account recommendations found in Leech et al.[264] Data were entered into SPSS package, version 15 for Windows.

5.13.2 Data analysis; Data screening

Exploratory data analysis (EDA) was conducted. This involved doing some descriptive statistics in order to become familiar with the data and checking for problems, outliers, missing data, and data entry mistakes. In addition EDA helps in the analysis.[264]

Mistakes were checked by cross-tabulation for impossible or unlikely combinations. For example, a person with a cervical level injury could not have paraplegia. For continuous data, scatterplots and boxplots were used to check for outliers[17] and data errors. When found, outliers were checked and, if appropriate, deleted from the specific part of the analysis.[147] When an outlier is eliminated this is stated in the relevant tables.

Missing responses existed in two forms; 1) when the participant had either forgotten or deliberately skipped a question, and 2) when data were missing because the response was not applicable to the respondent. The latter was noted a lot in the PRI section of the SF-MPQ. It was obvious that a large number of respondents only ticked those descriptors that applied to them and the missing cases were not "truly" missing. Therefore an explicit rule was created and the developer of SF-MPQ, Prof. Melzack was contacted for advice. Prof. Melzack agreed with the rule of how to treat missing data in this case (Appendix 4; Section 4.2.2). Returned questionnaires which had 50% or more missing data were excluded from the analysis.

5.14 Data analysis; Statistical tests; general

This section will explain the specific statistical tests selected for data analysis and the reasons for their selection. Quantitative methods were used for the analysis of the data which included descriptive statistics, comparisons between groups and correlation analysis. Tables and graphs were used throughout the results to describe groups and summarise findings. The statistical test chosen for comparisons or correlations depended on 1) the level of data, 2) the number of groups to be compared and 3) fulfilment of the assumptions of the test.

[17] An outlier is an observation that differs a lot from others and can bias statistics.[145]

5.14.1 Comparisons; Categorical data; two groups

When two groups of the same variable were compared and data were categorical the chi-square goodness of fit test (χ^2) was used which is the proportion of a population distribution within one variable.

When there were two different variables examined with categorical data on a 2x2 table then the Pearson's chi-square test (χ^2) was used. This is based on looking at the difference of expected and observed frequencies. The assumption is that 80% of cells should have an expected frequency of at least five counts.[147,285] Chi-square is a non-parametric test, a category of tests believed to have less efficient characteristics than the parametric tests, however, having a large sample, as in the present study, makes non-parametric tests only a little less powerful than parametric tests.[321] When the assumptions of the Chi-square were violated its alternative, Fisher exact test, was used.[285]

5.14.2 Comparisons; Categorical data; more than two groups

When data were categorical but more than two conditions were compared, (e.g. three groups with two or more categories) the extended chi square (χ^2) was used. This test can only be based on a two-tailed hypothesis[203] and, if found to be significant, two group comparisons, using a post hoc test, must be conducted in order to identify where the difference lies. Post hoc analysis is explained later in Section 5.18.

5.14.3 Comparisons; Continuous data; two groups

To compare differences between the means of two groups the independent t-test, which is a parametric test was used. Assumptions of the test are 1) a normal distribution, 2) homogeneity (equal variances), 3) different population in the different groups and 4) at least interval level data.[147] T-test can be used when the data is continuous on one variable and dichotomous on the other.[285]

According to Peacock & Kerry[350] even when there are deviations from the assumptions the t-test can still be used when the data:

1) May not be normal but is symmetric;
2) Is symmetric but have a digit preference;
3) Is moderately skewed but the two groups are even in size;
4) Is highly skewed but the groups are large (>50 in each group).

In the cases where the assumptions of the t-test were not met, the Mann-Whitney U test was used, which is the equivalent non-parametric test. It can also be used for relationships between a continuous or ordered variable and a dichotomous variable.[285]

5.14.4 Comparisons; Continuous data; more than two groups

When comparing means of more than two groups the one-way ANOVA was used. This is an extension of the t-test and has three assumptions: 1) data are continuous, 2) data are normally distributed within groups and 3) equal variances.[285,350]

It has been claimed that breaking the assumptions of ANOVA does not matter a lot but when the group sizes are not equal ANOVA is affected by skew and non-normality.[147] If the assumption of equal variances is violated, when group sizes are not the same, then ANOVA can be affected.[147] When assumptions were not met the non-parametric equivalent Kruskal-Wallis H test was used. This can be used for ordinal/continuous data.[147] ANOVA can only indicate the existence of a difference between the groups but not where the difference lies.[147] Therefore, when ANOVA was significant a post hoc test was done.

5.15 Data analysis; Associations and correlations

The relationship between two or more groups was often examined looking at associations and correlations.

5.15.1 Associations and correlations; Categorical data

When data were nominal on a 2x2 table, the Phi (ϕ) test was used to test for the direction and strength of the correlations.[147,264]

When data were ordinal[285] or when one variable was interval/ratio and the other ordinal,[203] Spearman's rank correlation rho (ρ) was employed which uses the ranks of the data and not its values.[351] All the above are non-parametric tests.

5.15.2 Associations and correlations; Continuous data

When data were continuous Pearson's correlation (r) was used to measure the strength and the direction of the association between the two variables.[285] The assumption of the test is that at least one of the variables is normally distributed.[350] Pearson's correlation is a parametric test and when its assumptions were violated then its equivalent non-parametric, Spearman's rank correlation rho (ρ) was used.

5.16 Data analysis; Examination of interaction effect

The interaction effect between the country of residence and another independent variable (IV) which changed every time (e.g. gender, type of injury etc) on the outcome (dependent variable- DV) which was the various categories of pain, was examine. The main purpose was to investigate the role of the "country of residence" on the outcome as a co-effect with another independent variable. When the DV, the category of pain, was on a nominal level binomial logistic regression was used. The purpose was not to identify general predictors via this type of regression but solely to check the two-way interaction under investigation which can be done using logistic regression.[147] Thus, analysis focused only on the interaction effect. When data on the DV were continuous the interaction effect was examined using independent factorial design analysis.[147] This between-groups analysis uses two-way analysis of variance (ANOVA)[18] to examine

[18] Two-way analysis of variance (ANOVA) means that there are two independent variables.[145,283]

the effect of one variable on all relationships previously analysed by a one-way analysis. For example, differences in pain intensity per gender are initially examined using one-way analysis and, using two-way ANOVA, the effect of country on the relation between pain intensity and gender is inspected. The assumptions for two-way ANOVA are: 1) normal distribution and 2) equal variances between groups (homogeneity).

5.17 Data analysis; Checking for assumptions

As seen above the parametric tests have assumptions that need to be met in order for the test to be used. Often these assumptions are similar. The procedure to check for these main assumptions is explained below.

5.17.1 Checking for assumptions; Normal distribution

All the parametric tests used have the assumption of a normal distribution. This is checked by looking at histograms and bell-shaped curves. Normal distribution is characterised by a bell-shaped curve and deviations from normality are; 1) lack of symmetry (skew) and, 2) pointiness (kurtosis). Both skewness and kurtosis should have a value of 0.[147] Checking the normal distribution via a histogram when the sample is small is not very reliable and examining the normal Q-Q plot is a more reliable method.[28] This plot shows the cumulative frequency distribution of the data against the cumulative frequency distribution for normal distribution.[28] The closer the distribution of the data to the line of the normal distribution, the more normally distributed the data.

Normal distribution can also be examined by the Kolmogorov-Smirnov (K-S) test which checks if the distribution deviates from a comparable normal.[147] If K-S is significant ($p \leq 0.05$) then the distribution is not normal. When used with large samples a significant result may not necessarily mean a deviation from normality. In this case any decision should be based on looking at the data and the extent of non-normality.[147]

Decisions about normality of the distribution, for the current study, were based on a combination of examining all the above.

5.17.2 Checking for assumptions; Equal variances

To check for equal variances, Levene's test was used. When the test is significant ($p \leq 0.05$) the assumption of homogeneity of variance is violated whereas, if not significant ($p > 0.05$), then the variances are equal and homogeneity accepted.[147]

5.17.3 Checking for assumptions; When assumptions are violated

When assumptions are violated transformation can be used to correct problems with the distribution and enable the use of a parametric test. However, this is a complicated procedure[147] and often the reader finds interpretation of the results difficult.[350] With a large sample, as in the current study, using a non-parametric test is only a little less powerful than using a parametric test.[321] It was decided not to do transformation of the data when assumptions of the distribution were violated but use a non-parametric test instead. In some cases, where assumptions slightly deviated from normality but could still be accepted both parametric and non-parametric tests were used in the analysis. Finally, in the case where both normal distribution and equal variances could not be assumed then the non-parametric test was applied.

5.18 Data analysis; Post hoc analysis and multiple testing

In the case where a statistical significance was found between more than two groups then, in order to identify between which groups the difference laid, a post hoc test was done.[275] Post hoc analysis is only appropriate for a two-tailed hypothesis.[147]

If multiple significance tests are applied to the variables then the possibility of a Type I error increases the risk that one in 20 of tests on the same sample may be found significant due to chance.[28] A Type I error is when a genuine effect in the population is believed but, in reality, there is no such effect (i.e. wrongly supports the alternative

hypothesis). A Type II error is when no effect in the population is believed but, in reality, there is one (i.e. wrongly supports the null hypothesis). As Type I error decreases, the probability of making a Type II error increases.[147] It is essential that the post-hoc test corrects for Type I error. Often multiple tests are done for separate individual tests (maybe examining different hypotheses but using the same variables), so the variables, though appearing independent, may not be independent. In these cases, Bonferroni can also be used to reduce Type I error.[28,351]

There are different methods of multiple testing. The Bonferroni correction corrects the cut-off point for multiple testing, controls very well for Type I error but it is found to be a conservative test.[147,351] Bonferroni is easy to conduct as it is mainly a division of the alpha level to the number of comparisons: if $\alpha=0.05$ and the number of comparisons 10 then for the test to be significant it should be $\alpha=0.05/10=0.005$. When the statistical test used is not parametric (e.g. chi square), then the most appropriate method to use is the Bonferroni correction.[275] Because the test is conservative one can be selective about the number of two-group comparisons to be made[147] which will result in a less conservative level of alpha value after Bonferroni correction.

Apart from being used for post hoc analysis, Bonferroni correction has also been used while doing multiple correlations.[4,91,344,436] Games-Howell is an accurate post-hoc test for controlling Type I error when the sample has unequal variances and also when sample sizes are unequal but it is too liberal when sample sizes are small. Field[147] recommends running Games-Howell in addition to any other selected post hoc test.

In this study, the following were made in relation to multiple testing:

1) When using multiple correction for many *separate individual tests* conducted; At the beginning of each result's chapter (Chapters 6 – 9) the number of times a variable of interest is involved in individual tests is given. The alpha level for each variable is set accordingly using the Bonferroni correction;
2) When using multiple correction for *post hoc pair comparisons* (done to identify where the significance is after one single test);

a. If a statistical significance was found after having used a non-parametric test then Bonferroni was used (by hand calculation);

b. If a statistical significance was found after having used a parametric test then post hoc tests were provided as an option on the SPSS programme. If only a few pair-comparisons needed to be done then Bonferroni was calculated manually.

3) Games-Howell was used, for cross – checking, in all cases as an additional post hoc. It will only be reported if there are discrepancies between the post hocs.

5.19 Data analysis; Sample size

A sample size calculation was conducted prior to the data collection for this study and 185 people were identified to participate (Section 5.6.1). This number of participants was exceeded. When comparing between groups, the size of each group may be of importance for the selection of the statistical test to be used. Some people consider a group size to be large if more than 50 people are included,[350] whereas others will do so if more than 30 are included.[265] This study usually had a large number of people in each group (>50) when making comparisons or checking for relationships. On the occasions where group sizes were small or very small then non-parametric tests were used.

5.20 Data analysis; Significant testing and alpha level

There are three types of significance; the statistical, the practical and the clinical significance.[445] A statistically significant test is used in order to explore the likelihood that a hypothesis about a group is true or not true.[351] Usually the null hypothesis is tested and this is generally called Null Hypothesis Significance Testing (NHST).[78] To measure the result of the NHST the p-value is used. The level of the p value is the alpha level (α-level) which is the probability of making a Type I error.[147] Usually, the α-level chosen is 0.05 which means that there is 5% probability of wrongly supporting

the alternative hypothesis.[147] The alternative hypothesis can be two-tailed, which allows for the relationship between the variables examined either way. Or it can be one-tailed, which allows it only to be in one direction.[351] One-sided hypotheses should be avoided unless there is clear justification for doing so.[351]

Because statistical significance has been negatively criticised over the past few decades, practical and clinical significance have been proposed. Practical significance evaluates the relationships by explaining the practicality of the findings and it uses effect sizes to do so.[445] Clinical significance indicates if an intervention makes a difference to people's everyday lives.[445]

As no intervention was applied in this study, clinical significance was not applicable. But, both the statistical and practical significance have been evaluated for all research hypotheses. For statistical significance the α-level chosen was set to $p \leq 0.05$. This, however, changed depending on the Bonferroni correction. As there was no prior evidence in the literature that could justify the use of one-tailed testing for most of the variables under examination in iSCI, all tests were two-tailed.

5.21 Data analysis; Effect size

The NHST has been criticised as not adequately answering the questions, leading to misinterpretation of findings and not properly evaluating the importance of the results.[78,146,445,492] For a null hypothesis to be true the effect size (ES) should be 0 but this can never be really true because two random samples will always have some small difference in their means.[78] Since the ES can never be 0 in reality the null hypothesis can never be true either. The p-value "accepts" or "rejects" the null hypothesis, which, then, can be misleading.[78,147,492] A better explanation of the findings can be given if the ES and the confidence intervals (CI) are also reported.[78]

The effect size gives information on the strength of a relationship between the IV and a DV.[264] It is considered an "*index of degree of departure from the null hypothesis*".[79] The larger the ES, the greater the power of the test and the smaller the size of the

group needed to identify a relationship.[79] Generally, there are four major categories of ES[146] but two are the most commonly used, the "r" and the "d" family. The "r" family expresses the ES in strength of association[146,264] and the "d" family expresses the ES in terms of difference between two or more groups.[79]

One of the following, ES, has been used for each research hypotheses in this study depending on the statistical test used:

- From the "d" family the most commonly used is Cohen's d which is used when data is categorical.[146] It is recommended to use Kendall's τ when data is ordinal;[146]
- When conducting ANOVA the ES of choice should come from the "eta" (η) or "omega" (ω) categories. SPSS by default only calculates the partial eta-squared when ANOVA is conducted, but this type of ES is considered to be inappropriate for use in ANOVA.[340] In between group designs the Omega squared (ω^2) should be the ES of choice.[340] Unfortunately, this is not calculated in SPSS and it is complicated to do by hand. Eta squared (η^2) can also be used with ANOVA, and although it may slightly overestimate the effect,[340] it is much easier to do manually and for this reason was preferred;
- When using Pearson's correlation the ES used was the "r" and when using Spearman's ρ correlation the ES used was the "ρ". The value range for the "r" and "ρ" are identical;[146]
- When chi-square goodness of fit or independent chi-square are used the most appropriate ES to use is the phi (ϕ). When for a table greater than 2x2 then Cramer's v is preferred;[79,264]
- When the Mann-Whitney U test was used then the effect size was computed by converting the z to r using a given formula.[147,264]

5.22 Data analysis; Confidence interval (CI)

When studying the mean of groups it is of interest to use the mean of the group as an estimate of the value in the population.[147] The means of the groups can have different values and by calculating the boundaries within which the true value of the mean is believed to be then the accuracy of the mean is assessed.[147] These boundaries are the confidence intervals (CI). Typically, a 95% CI is used which suggests that one can be 95% confident that the true value of the mean of the population lies within the CI given.[28,351] CI can take other limits like 99% or 90%.[8,147,351] The CI can be used in the following ways:

- The 95% CI is usually used for large groups (n>100 for total group);[351]
- If the group size is smaller then the data need to be normally distributed and the t-distribution is used to calculate the CI.[147,351] If data are skewed then the CI can be calculated by the median, which if done in small groups can be rather wide, but it is preferable to using the mean if data are skewed;[8]
- In the case when CI is calculated for proportions then a large group size (to enable 95% CI) is when the number of responses with the condition (r) (e.g. people with pain) and the n-r (where n=total number of participants) are in both cases greater than 5;[351]
- To calculate CI for correlation the r needs to be converted into a z value, using a formula to identify the CI limits which are then back converted in to r values.[147] This formula was used to find the CI of all related correlations in the current study. The Fisher transformation can also be used to calculate the CI for Spearman's correlation.

When interpreting results the following need to be taken into account:

- For the p value to be significant the CI must not include zero;[8]
- When the CI of the mean is small then the mean of the group is a good representative of the true mean of the population.[147]

In this study, 95% CI were calculated for means, proportions and correlations for all hypotheses.

5.23 Methods of analysis for translation and validation of SCIM III into the Greek language

It is important that when translating and validating a measure in one language or validating it for use under different circumstances to evaluate its reliability and validity.

5.23.1 Reliability

There are five general types of reliability, 1) inter-rater, 2) test-retest, 3) parallel forms, 4) internal consistency and 5) sensitivity to change. Inter-rater reliability is given by the result of agreement on one item between two or more raters.[36] Test-retest reliability measures the ability of the test to remain stable over a period of time.[36,447] Parallel forms reliability checks how consistent the results of two tests that are constructed in the same way from the same content, are.[447] Internal consistency investigates the homogeneity by looking at the extent to which the questions (items) relate to a particular dimension (construct) in a measure.[36,447] Finally, sensitivity to change is the ability of the measure to capture a change in the outcome of the people who complete the measure.[36]

In this study, inter-rater, test-retest and sensitivity to change reliability could not be performed due to the design of the project. Internal consistency was tested. There are various ways to test internal consistency; Cronbach's alpha (α), multiple form, half split, item-item and item-total.[36] The most commonly used is Cronbach's α which produces an estimate of reliability using all possible correlations. The "rules of thumb" for Cronbach's α are: >0.9 Excellent, >0.8 Good, >0.7 Acceptable, >0.6 Questionable, >0.5 Poor and <0.5 Unacceptable.[164] In the case of research tools a satisfactory Cronbach's α is between 0.7 and 0.8 but in the case of a clinical situation a higher

Cronbach'a α is recommended (minimum 0.90).[27] For this study, a 0.7-0.8 level is satisfactory.

Cronbach's α can be affected by multidimensionality which affects its precision, thus it should be used when there is only one single common factor in order to measure the strength of this factor.[83] Therefore unidimensionality should be established first by principal component analysis (PCA).[83] PCA was used in the present study to confirm the unidimensionality of SCIM III for the Greek version before applying the Cronbach's alpha to check for internal validity. The same was done for the English version despite the fact that the original version of SCIM III had established unidimensionality of the subscales by using factor analysis.[65] This was done because in the current study SCIM III was used under different conditions (by self-reporting).

PCA reveals the underlying structures in complex data sets and it identifies the importance of each dimension of the data.[403] The assumptions for PCA are; 1) data is normal to the extent that skewness or outliers do not affect the observed correlations or the tests performed and 2) data should be correlated in a linear way.[264] Linearity was checked via scatterplots. For conducting PCA two tests are taken into account; the Kaiser-Meyer-Olkin measure of sampling adequacy (KMO) test which tells if enough items are predicted in one factor. Its values range from 0 to 1, a value near 0 can indicate that factor analysis is inappropriate for the data and a value near 1 that the factors are reliable. Values below 0.5 should not be accepted, 0.7 - 0.8 are good and 0.8 - 0.9 are excellent and above are superb.[147] The second test conducted was the Bartlett's test of sphericity which should be significant to indicate that the variables are correlated enough to give a reasonable basis for doing factor analysis.[264]

5.23.2 Validity

There are many types of validity but the main four are 1) criterion, 2) concurrent, 3) construct and 4) content validity. The first two can be grouped together. Criterion validity refers to how much the measure under examination correlates with another measure already accepted and validated. Concurrent validity, which is part of the

criterion validity, investigates if the measure actually measures what it intends to measure.[36] In this study criterion/concurrent validity could be examined for two of the subscales of SCIM III which were similar to two of the subscales of EQ-5D; self-care and mobility.

Construct validity is the degree to which conclusions from the study can be correctly drawn according to the theoretical constructs that they were based on.[447] In other words, the test actually measures what it is designed to. Construct validity can be examined by checking if the expectations of the results have been achieved, by using correlation matrices and with factor analysis. When two tests are designed to measure the same construct a good correlation between them is predicted.[89] In this study, this was examined via concurrent validity in which two of the subscales of SCIM III and EQ-5D were tested for correlation. According to Cronbach and Meehl,[89] another way to support construct validity is to examine the internal consistency and homogeneity of the measure. They claimed than even if correlations are low but they are consistent this can give support to the fact that the sample is describing a generalised tendency.[89] As explained earlier, internal consistency was determined by applying Cronbach's α and homogeneity by applying PCA.

Finally, content validity is the extent to which the content of the measure is logical enough to examine the characteristics or concept that it intends to examine. This is achieved by judgements from the panel who develop the measure.[36] As SCIM III was previously developed and examined for its content validity this was not examined further in the current study.

5.24 Additional note on presentation of results

All results that pass the α-level ≤0.05 will be presented in the tables in the results chapters and in the appendices. Those, however, that pass the Bonferroni correction level will be in bold. These will be considered the statistically significant results for the study. In post hoc multiple comparison analysis the statistically significant level

calculated for the particular analysis will be given each time, and the results passing the significance level will also be marked in bold.

5.25 Conclusion

This chapter explored the methodological background and described in detail the methods followed in order to collect data appropriate to answer the aim, questions and hypotheses of this project. Cross-national research has been considered a valuable method of research for many years and internet research is now used more frequently. Both types have advantages and disadvantages which have been presented in this chapter focusing on the steps taken to reduce bias and increase RR. This chapter also presented the methodology of the statistical analysis followed including that for examining the psychometric properties of SCIM III.

The next chapter is the first of four chapters to present the data analysis of the survey. This chapter will describe the socio-demographic profiles of the group and examine the experience of pain focusing on LBP.

Chapter 6; Results: Demographic profile and pain characteristics

Chapter Brief Table of Contents

"Aw, people can come up with statistics to prove anything, Kent. Forty percent of all people know that."

- Homer Simpson, from The Simpsons episode: "Homer the Vigilante"

6.0 Introduction

The previous chapter described in detail the methodological steps followed to achieve data collection. In addition, the selection of the specific standardised tools used was justified and a description of the methods employed for statistical analysis explained.

This chapter is the first of a series of four to present results. Its main aim is to respond to the thesis's primary research question "Do people with iSCI have LBP, and what is their present and usual pain experience?" The chapter divides in two parts; part 1 will perform the analysis of the translation of the socio-demographic profile section of the questionnaire and will continue with presenting the findings of the profiles of the respondents. The second part will focus on the characteristics of LBP in relation to its quality and intensity. In addition, pain location and extent on the body will be examined in this chapter.

Part 1; Translation and respondents' profiles

6.1.1 Translation and piloting of socio-demographic profile questions

There were five forward translators[19], who were given the original version of the questionnaire. They were of Greek origin, living in the UK for a mean of 7.7±5.2 (mean±SD) years, thus having a good knowledge of the English language and culture. They needed 6.8±4.6 (mean±SD) hours to translate the questionnaire including time to give feedback. For each question they were asked to rate the difficulty of translating it on a 0-10 NRS ranging from "very easy" to "the most difficult" to translate. The overall difficulty of translating the questionnaire was low (2.6±2.6, mean±SD) with the easiest questions rated as 0.4±0.5 (mean±SD) and only one rated as moderately difficult (4.6±3.0, mean±SD) to translate (Appendix 5: Table 5.1.1).

Feedback from the forward translators led to some format changes in the questionnaire. The back-translator[20] was an English teacher of Greek origin, who had been living in the UK for 10 years. She spent 13 hours on the back-translation, rarely used the dictionary and rated the easiness of the translation as 4 (0-10 NRS). The pilot of the questionnaire led to minor reformatting. Some important changes following translation, feedback and piloting can be found at Appendix 4. Following the second pilot stage[21], given to the Greek group, the most important changes can be found at Appendix 4. The final Greek questionnaire can be found at Appendix 3.

[19] Forward translation is the procedure for translating a document from its original language to the target language; in this case from English into Greek. For details see Chapter 5.
[20] Back-translation is the procedure for translating the document from the target language back into the source language; in this case from Greek into English. For details see Chapter 5.
[21] For details on the sequence of the pilot stages see Chapter 5.

6.1.2 Results; data cleaning

During the first stage of data analysis, while conducting EDA[22], the data were checked for responses that were not appropriate to enter in the analysis. In total 282 people returned the questionnaire either online or via the post but 219 entered the data analysis (Table 6.1.1). The initial plan of the study was to recruit participants from Canada as well, however collaboration with a Canadian association could not be established at the time and no Canadian online site was identified, thus making recruitment from this particular country inappropriate. Six Canadians completed the survey (via other websites) but it was a very small group and it was therefore decided to exclude them. Four further people from various countries were identified but excluded.

A further 20 people (7.1% of initial group) were excluded because they had stated that they did not know the type of their injury. Their responses were double checked and the author believes that 16 of them could possibly have incomplete injuries (5.7% of initial group). Of these 20 people, 13 came from the USA (8.6% of USA initial group), five from Greece (8.6% of Greek initial group) and two from the UK (3% of UK initial group – 2/77). Three people (1.1%) completed less than 50% of their questionnaire and were excluded.

Twenty eight people with a complete injury completed the survey but analysing their data were beyond the scope of the study, hence these questionnaires were excluded.

Many people viewed the survey online but dropped out before completing it, in total there were 283 people from all three participating countries. Thirty six (36%) of them gave information about their pain presence: 34% had pain post their injury and 2% did not have pain. The remaining 64% of those who dropped out did not give any information about their pain status. The data from the dropped out respondents were not analysed further as it was beyond the scope of the study.

[22] For details about EDA see Chapter 5, Section 5.13.2

As explained in Chapter 4, there are difficulties with precisely calculating the return rate of questionnaires for surveys which follow an online methodology but a calculation of "complete rate" was made based on how many people viewed the survey online and how many completed it. The highest online completion rate was from the UK (52.3%) followed by the USA (43.3%) (Table 6.1.1).

Table 6.1.1: Completed, returned and excluded questionnaires

Arm country	Web survey			Mail questionnaires returned	Excluded from study (both from e-survey and paper survey)
	Number of people who viewed all or part of the questionnaire	Number of people who completed the questionnaire	Complete rate (%)		
USA	344	149	43.3%	1	Complete injury n=28 Type of injury not known n=20 Other country n=10 50% missing data n=3 Non SCI n=2
UK	132	69	52.3%	5	
Greece	37	12	32.4%	46	
Total	513	230	44.8%	52	
Total completed questionnaires: 282					
Excluded questionnaires: 63					
Total included in study: 219 **USA n=122** **UK n=52** **GR n=45**					

6.1.3 Bonferroni correction

As explained in Chapter 5 (Section 5.18), Bonferroni was used in two ways; 1) for post hoc analysis and 2) when multiple independent tests were conducted using the same main variable of interest. In the current chapter, depending on the number of multiple tests done on the variable of interest the α-level of statistical significance set by Bonferroni ranged from p≤0.005 – 0.007 (Appendix 5: Table 5.2.1).

6.1.4 General results

Two hundred and nineteen (219) respondents completed questionnaires which were included in the data set. They were mainly males (62.3%), with an average age of 50.3±14.4 (mean±SD) years. Mean time since injury was 11.6±10.7 (mean±SD) years and mean age at injury was 38.6±16.2 (mean±SD) years. The majority were married (57%). Their education level varied from high school (24.1%) to college (21.8%) or university degree (21.8%). Most respondents were either employed (28%) or retired (24.2%), while many reported that they could not work due to their iSCI (25.1%). For those who worked, the mean working hours per week were 24.2 ±13.3 (mean±SD) (Table 6.1.2).

Cause of injury was mainly traumatic (70.8%), with road traffic accidents accounting for half of the injuries and sport injuries for 21.4%. Falls were responsible for 9.6% of the injuries and happened in various places including work, home, stairs or due to a slippery surface. Among the non-traumatic causes of injury, degenerative conditions were the most common (21.9%) (mainly osteoporosis), followed by a vascular cause (18.8%) and then by a spinal deformity (12.6%). For 18.8% of the cases, more than one reason was the cause of the non-traumatic injury (Table 6.1.3). 52.9% of respondents had an incomplete paraplegia.

6.1.5 Pain, MSKP and LBP prevalence

The respondents were asked to report on their pain in general and other types of pain in particular including MSKP, LBP and BP. They could choose all types of pain that applied to them. A very high number of the respondents (91.3%) reported having pain in general. Eightly three participants reported having MSKP which was a prevalence of 38.8%. Among people with pain only, the prevalence of MSKP rose to 42.6% (Table 6.1.4). Some further information related to participants' characteristics, not analysed in detail at present, can be found at Appendix 5, Table 5.3.1.

Table 6.1.2: General demographic profile of the survey respondents

Variable (n=number of responses)	Mean ± SD, % or min-max
Sex (M/F) (n=215)	62.3/37.7
Age (years; mean ± SD; min-max) (n=211)	50.3 ± 14.4, 19.8-91.7
Time since injury (years, mean ± SD, min-max) (n=218)	11.7 ± 10.7, 0.3-44.2
Age at injury (years, mean ± SD, min=max) (n=210)	38.6 ± 16.2, 0.0-78.3
Ethnic group (%)	
White – UK	22.4
White Greek	21.0
Other White or other European	38.3
White American (including American Indians, Spanish/Hispanic)	12.2
Other Asian	1.4
Black; Caribbean, African & other Black	0.9
Mixed – White & Asian/Other mixed	3.3
Mother Tongue (%) (n=218)	
English	75.7
Greek	20.2
Other	4.1
Marital status (%) (n=214)	
Married	57.0
Living with partner	6.5
In a relationship	2.8
Separated/Divorced	8.9
Widowed	6.5
Single	17.8
Other	0.5
Education (%) (n=216)	
PhD or equivalent	3.2
Master's	13.9
University Bachelor Degree	21.8
College or equivalent	21.8
High School	24.1
Other	4.2
No diploma/degree	11.1
Employment (%)* (n=219)	
Employed	27.9
Self-employed	15.5
Voluntary work	11.0
Working from home	9.6
Receive health benefits	19.2
Looking for a job	5.0
Unemployed but was working before iSCI	16.0
Unable to work due to iSCI	25.1
Unemployed and never had a paid job	0.9
Homemaker	6.8
Retired	24.2
Student	4.6
Other	5.0
Working hours per week (mean ± SD, min-max) (n=53)	24.2±13.3
Type of injury (%)	
Incomplete tetraplegia (n=100)	45.7
Other incomplete tetraplegia (n=3)	1.4
Incomplete paraplegia (n=112)	51.1
Other incomplete paraplegia (n=4)	1.8

*Total sums to greater than 100% as respondents were allowed to choose more than one option. Abbreviation: SD, Standard Deviation.

Table 6.1.3: Cause of injury

Cause	%	Cause	%
Cause of injury (n=219)			
Traumatic (n=155)	70.8	**Non-Traumatic** (n=64)	29.2
Cause of Traumatic Injury (n=154)		Cause of Non-Traumatic Injury (n=64)	
Road Traffic Accident	50.0	Vascular	18.8
Bicycle Accident	5.8	Embolism	6.3
Car Accident	30.5	Epidural Haemorrhage	3.1
Motorbike/ATV Accident	11.7	Other vascular	9.4
Pedestrian Accident	1.9	Cancerous	4.7
Gunshot/other violence accident	1.9	Inflammations & Infections	7.5
Work Related Accident	2.6	Sacroidosis	1.6
Falling off		Transverse Myelitis	4.7
Ladder/Stair/scaffolding/other	2.6	Degenerative	21.9
Domestic Related Accident	7.1	Osteoarthritis	3.1
Falling down Stairs	3.2	Osteoporosis	10.9
Falling out of Window	0.6	Rheumatoid Arthritis	6.3
Slippery Floor/trip over object on floor	3.2	Other degenerative	1.6
Sport Accident	21.4	Spinal Deformity	12.6
Climbing	1.3	Kyphoscoliosis/Spinal Bifida	3.2
Diving	5.2	Spondylolisis/Spinal hernia/Spinal stenosis	9.4
Horse Riding	1.9	Other Neurological	4.7
Motorbike Racing	2.6	Cerebral Palsy/Multiple Sclerosis	4.7
Skydiving/paragliding	3.2	Other not above	7.8
Swimming/body surfing/scuba diving	1.8	More than one of the above reasons	18.8
Skiing/snow boarding	2.6	Medical mistake at surgery	4.7
Other sport related	2.5		
Other Traumatic Cause of Injury	5.8		

LBP could be established for four time periods; 1) occurrence of LBP at any time post iSCI (Life prevalence LBP post iSCI) which was reported at 73.5% for the total group (80.5% among people with pain only), 2) current LBP at the time of completing the questionnaire (Point prevalence LBP) which was reported as 67.9% (74.6% among people with pain only), 3) LBP over the last 1 month (1 month LBP prevalence) reported as 68.4% (75.1% among people with pain only) and 4) LBP over the last 3 months (3 months LBP prevalence) reported 70.1% (77.1% among people with pain only) (Figure 6.1.1). Throughout this chapter, in most cases, all types of LBP time period prevalence were used in the analysis. However, analysis in the following chapters will only examine "current LBP prevalence". The reason for selecting this LBP prevalence was twofold, first, because it does not raise issues related to memory bias and, second, because in general current prevalence is most commonly reported in the literature and thus comparisons to other studies may be feasible.

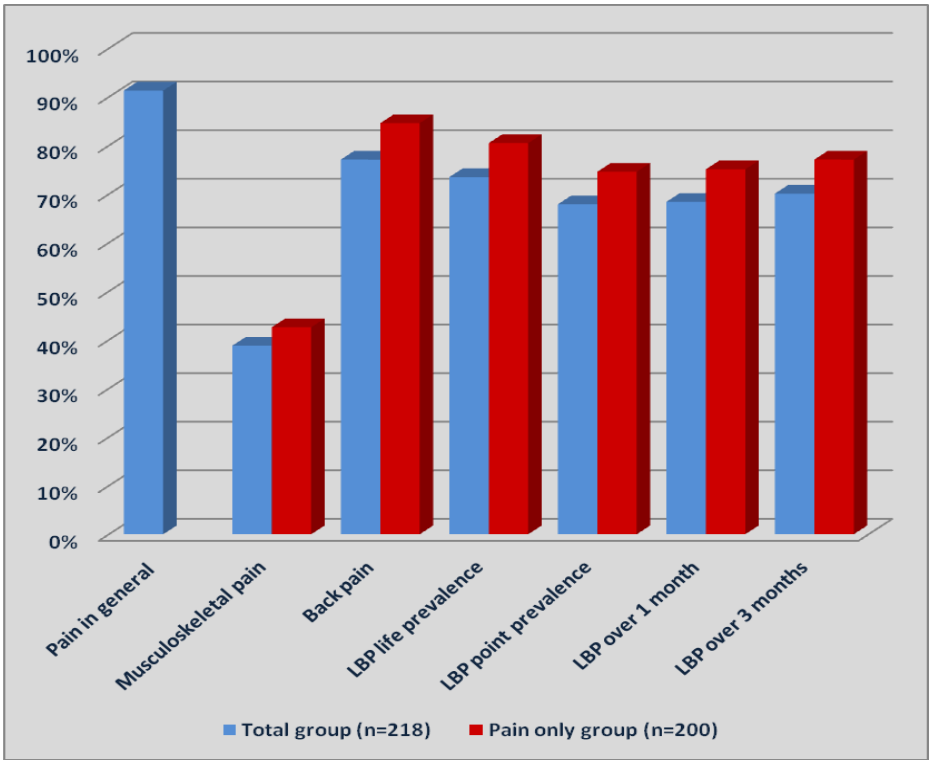

Figure 6.1.1: Percentage of people reporting pain categories examined.
Abbreviations: LBP, Low back pain.

Significantly more people reported pain post their iSCI (n=200) than no pain (n=19), prevalence 91.3% (95% CI 86%, 94%, p≤0.001, χ^2=149.5, goodness of fit chi-square,) and the effect of this difference was larger than typical (ES ϕ=0.82). Similarly, significantly more people reported having back pain (n=165) than those who did not (n=49), prevalence 77.1% (95% CI 71%, 82%, p≤0.001, χ^2=62.87, goodness of fit chi-square) representing a larger than typical effect (ES ϕ=0.54).

The primary research question aimed to investigate if people with iSCI had LBP and what was their present and usual LBP. The primary hypothesis was:

Hypothesis 0 (null): In people with iSCI there is no significant difference in the percentage of those with LBP and those without.

Hypothesis 1: In people with iSCI there is a significant difference in the percentage of those with LBP and those without.

More people reported having LBP since iSCI onset (n=161) compared to those who did not (n=58), prevalence 73.5% (95% CI 67%, 78%, p≤0.001, χ^2=48.44, goodness of fit chi-square, ES: ϕ=0.47). More people reported having current LBP (n=144) than those who did not (n=68), prevalence 67.9% (95% CI 61%, 73%, p≤0.001, χ^2=27.24, goodness of fit chi-square, ES: ϕ=0.35). More people reported having LBP over the last month (n=145) than those who did not (n=67), prevalence 68.4% (95% CI 61%, 74%, p≤0.001, χ^2=28.69, goodness of fit chi-square, ES: ϕ=0.36). Finally, more people reported having LBP over last 3 months (n=148) than those who did not (n=63), prevalence 70.1% (95% CI 63%, 75%, p≤0.001, χ^2=34.24, goodness of fit chi-square, ES: ϕ=0.40,). In all cases the differences were statistically significant and the effect sizes were medium. The null hypothesis can be rejected. In the case of MSKP the opposite happened, significantly less people reported having MSKP (n=83) compared to those who did not have MSKP (n=131), prevalence 38.8% (95% CI 32%, 45%, p≤0.001, χ^2=10.76, Chi-square goodness of fit) however, it had a small effect size (ES: ϕ=0.22).

6.1.6 Relationship between LBP and MSKP

The type of pain felt in the lower back area was examined to see if it was related to MSKP. This hypothesis was not set at study onset but developed in the process. This was done by examining if a correlation between the two variables existed. The hypothesis was:

Hypothesis 0 (null): There is no significant association between LBP and MSKP in people with iSCI.

Hypothesis new: There is a significant association between LBP and MSKP in people with iSCI.

The Phi test (ϕ) was applied to a group of 213 people and a positive significant correlation of medium strength was found between LBP (lifetime) and MSKP, ($p \leq 0.001$, $\phi = 0.331$, 95%CI 0.23, 0.42), suggesting that the more people report LBP, the more people report MSKP. The same positive and statistically significant correlation was found between the other reported time periods of LBP and MSKP; between current LBP and MSKP: $p \leq 0.001$, ($\phi = 0.33$, 95%CI 0.23-0.45, n=207); between LBP over the last 1 month and MSKP: $p \leq 0.001$, ($\phi = 0.30$, 95%CI 0.19, 0.39, n=210); and between LBP over the last 3 months and MSKP: $p \leq 0.001$, ($\phi = 0.27$, 95%CI 0.16, 0.37, n=207). The null hypothesis can be rejected as a positive correlation between MSKP and LBP has been shown.

6.1.7 Pain, MSKP and LBP; relation to demographic profile characteristics

People with and without the pain categories were compared for differences in their demographic profiles including sex, cause of injury, age, level of injury and time since injury. Two analyses were made; one included the total group of participants and one included only people with pain.

Though women (n=76) reported MSKP and LBP significantly more often over the last 3 months this failed to remain significant following the Bonferroni application (Table

6.1.4; Appendix 5: Table 5.4.1; Figure 5.4.1). Among people with pain only, no significant difference was found between males and females in their LBP presence over the last 3 months (Appendix 5: Table 5.4.2).

The consensus report by IASP[177] said that research hypotheses should be tested in both sexes. As seen in the paragraph above a difference between males and females in the MSKP and 3 months LBP was found but only pre-Bonferroni application. Therefore, further analysis will not be part of this main analysis. However, it was conducted in this case, and it is presented at Appendix 5. (Appendix 5: Table 5.4.3).

Analysis showed that although some differences in the presence of the pain categories between people with traumatic and non-traumatic cause of injury were found, only one passed the Bonferroni level of significance (Table 6.1.4; Appendix 5: Figure 5.4.2 and Tables 5.4.4, 5.4.5). A significantly higher proportion of people with non-traumatic cause of injury (78%) than those with a traumatic injury (64%) reported current LBP ($p=0.003$, $\chi^2=4.37$, Pearson's chi-square) (Table 6.1.4).

The only results strong enough to pass the Bonferroni significance when the level of injury was examined related to LBP presence. A significantly higher proportion of people with paraplegia reported LBP compared to people with tetraplegia; lifetime LBP post iSCI: 84% versus 62%, $p\leq0.001$, ($\chi^2=12.93$, Pearson's chi-square); current LBP: 77% versus 58%, $p=0.003$, ($\chi^2=9.13$, Pearson's chi-square); LBP over the last 1 month: 78% versus 58% $p=0.002$, ($\chi^2=10.06$, Pearson's chi-square); and LBP over the last 3 months: 81% versus 58%, $p\leq0.001$, ($\chi^2=14.06$, Pearson's chi-square) (Table 6.1.4; Appendix 5: Table 5.4.6, Table 5.4.9; Figure 5.4.3).

Neither age nor time since injury impacted significantly on pain as no statistical differences were found between people with and without the pain categories examined (Table 6.1.4). Time since injury was divided into groups to examine if the results in the present study would match the finding reported by Siddall et al[406] that MSKP presents higher initially in the first 6 months post injury, then it drops and increases again at 5-years post injury. In the current study there were no participants who had sustained their injury less than 3 months prior to the study, thus time since

injury was divided into groups of 3-6 months, 7-11 months, 1-5 years, 6-10 years, 11-15 years, 16-20 years, 21-30 years and 30+ years. No significant difference was found in the mean time since injury between people with and without MSKP (χ^2=4.34, p=0.73, df7, extended chi-square, n=212). Dividing the groups into fewer categories (3-6 months, 7 months – 5 years, and 6 years and above), again no significant difference was found in the mean time since injury between people with and without MSKP (χ^2=1.79, p=0.40, df2, extended chi-square, n=212).

6.1.8 Pain and LBP; pain/LBP days, free periods, onset

Among people with pain, nearly 62% said that they felt pain (in general) and 44% LBP on a daily basis over the last six months. These were followed by 14.4% feeling pain between 1-9 and 10-20 days per month and 26.3% feeling LBP 1-9 days per month (Figure 6.1.2; Appendix 5: Table 5.5.1).

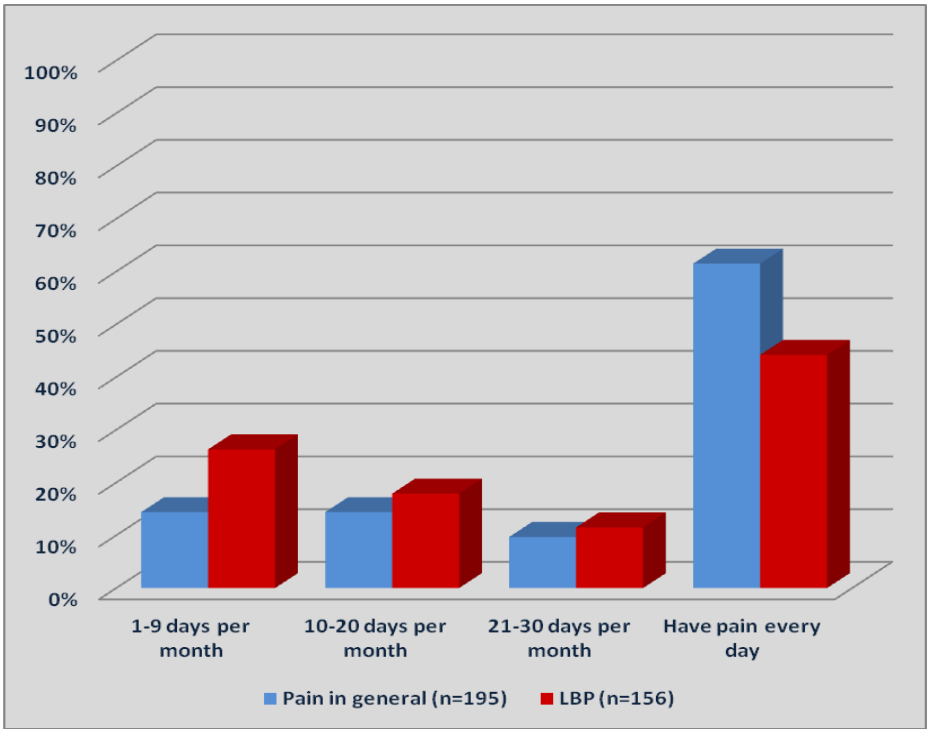

Figure 6.1.2: Percentage of people reporting number of pain and LBP days felt per month.
Abbreviations: LBP, Low back pain

Table 6.1.4: Summary results and statistics of categories of pain and demographic profile characteristics of the respondents

	Pain		MSKP		Back Pain		LBP lifetime		LBP current		LBP over 1 month		LBP over 3 months	
	N[1] (%)	Statistic P-value	N[1] (%)	Statistic P-value	N[1] (%)	Statistic P-value	N[1] (%)	Statistic P-value	N[1] (%)	Statistic P-value	N[1] (%)	Statistic P-value	N[1] (%)	Statistic P-value
Sex		X^2=0.53 p=0.46		X^2=5.39 p=0.02[2]		X^2=0.31.3 p=0.23		X^2=3.82 p=0.051		X^2=1.87 p=0.17		X^2=4.78 p=0.06		X^2=4.02 p=0.04*
Male	122 (91)		43 (33)		99 (75)		93 (70)		85 (65)		84 (64)		86 (66)	
Female	76 (94)		38 (49)		64 (82)		66 (82)		57 (75)		59 (77)		60 (79)	
Cause of injury		X^2=0.08 p=0.77		X^2=4.83 p=0.028[2]		X^2=2.73 p=0.09		X^2=4.01 p=0.04[2]		X^2=4.37 **p=0.003****		X^2=4.01 p=0.04[2]		X^2=3.97 p=0.04
Traumatic	141 (91		51 (34)		111 (74)		108 (70)		94 (64)		95 (64)		97 (66)	
Non Traumatic	59 (92)		32 (50)		54 (84)		53 (83)		50 (78)		50 (78)		51 (80)	
Age (mean±SD)	50.1±14.3 52.4±15.5	t=0.68 p=0.49 95%CI -4.5,9.2	51.4±15.5 50.4±13.2	t=-0.61 p=0.54 95%CI -5.1, 2.9	50.5±14.6 51.2±13.5	t=0.29 p=0.77 95%CI -4.0, 5.4	50.2±14.8 50.5±13.3	t=-0.49 p=0.61 95%CI -4.1, 4.8	51.0±14.8 50.3±13.5	t=-0.39 p=0.69 95%CI -4.9, 3.7	51.21±14.9 49.5±13.1	t=-0.77 p=0.43 95%CI -6.0, 2.6	50.8±15.0 50.2±13.0	t=-0.22 p=0.81 95%CI -4.9, 3.8
Level of injury		X^2=3.28 p=0.51		X^2=2.64 p=0.10		X^2=10.85 p=0.01[2]		X^2=12.93 **p≤0.001*****		X^2=9.13 **p=0.003****		X^2=10.06 **p=0.002****		X^2=14.06 **p≤0.001*****
Tetraplegia	90 (87)		33 (33)		67 (67)		64 (62)		57 (58)		57 (58)		57 (58)	
Paraplegia	110 (95)		50 (44)		98 (86)		97 (84)		87 (77)		88 (78)		91 (81)	
Time since injury	11.63±10.9 11.1±8.3	t=-0.20 p=0.83 95%CI -5.5, 4.5	12.6±10.4 11.2±11.0	t=-0.03 p=0.96 95%CI -4.3, 1.6	11.8±11.1 11.2±9.5	t=-0.30 p=0.75 95%CI -3.9, 2.9	11.6±11.1 11.5±9.5	t=-0.98 p=0.32 95%CI -3.3, 3.1	11.6±11.2 12.0±10.0	t=0.3 p=0.77 95%CI -2.8, 3.4	11.8±11.2 11.7±9.8	t=-0.06 p=0.95 95%CI -3.20, 3.0	11.8±11.0 12.5±10.3	t=0.61 p=0.53 95%CI -1.6, 4.5
Pain onset														
LBP onset		p=0.55 **p≤0.001*****												

[1] People with this type of pain, **Significant at p≤0.01 level, ***Significant at p≤0.001 level; **in bold:** significant following application of the Bonferroni correction; [2]not significant post Bonferroni correction

Abbreviations: LBP, Low back pain.

Statistical tests: χ^2, Chi-Square; t, independent t-test.

There was no question in this survey to specifically ask the number of MSKP days felt in a month. Looking at the differences in the number of pain days between people with and without MSKP provided some information on the impact of MSKP on the pain days. Out of the 195 people with pain, who replied to this question, people with (n=83) and without (n=112) MSKP did not differ on the number of pain days they reported per month (p=0.40, χ^2=4.9, Pearson's chi-square) (Appendix 5: Table 5.5.2).

The participants were asked to indicate if since the start of their pain or LBP they had any pain/LBP-free week. An administrator error led to the possible loss of some responses related to the LBP-free week question, however the number of responses remained large (n=123). More than half of people who reported pain did not have any pain-free weeks and just below 10% reported being pain free most of the time. Some 40% of respondents said that their LBP was constant and only about 14% said they were LBP-free most of the time (Figure 6.1.3; Appendix 5: Table 5.5.3).

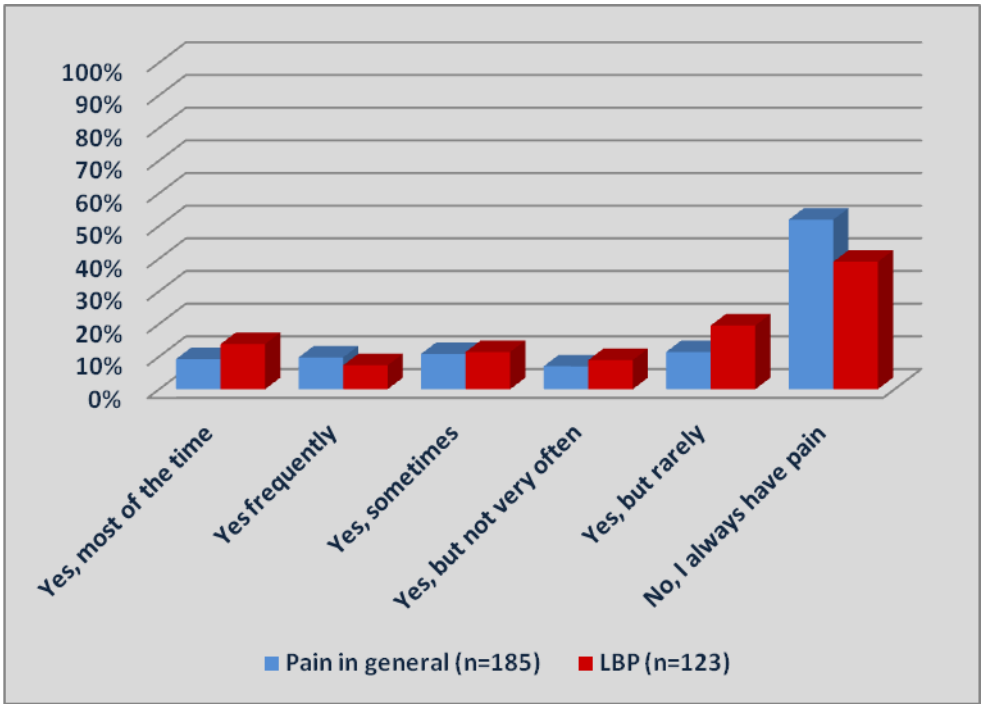

Figure 6.1.3: Percentage of people reporting frequency of pain and LBP free weeks
Abbreviations: LBP, Low back pain

Finally, people were asked to indicate the time of pain onset following their iSCI. Just under half of them (41.7%) said that pain started immediately after their injury; then, the new cases of pain dropped to just below 20% for the next 6 months. There was a low percentage of new pain cases between 6 months and 1 year, which slightly increased after 1 year (Figure 6.1.4; Appendix 5: Table 5.5.4). People were then asked particularly about their LBP onset which followed a similar pattern of onset during the first 6 months. LBP onset was common immediately after the injury (32.6%) and then it dropped to below 20% for the next few months. After 6 months post injury, the percentage of new LBP cases started increasing, particularly after 1 year.(Figure 6.1.4; Appendix 5: Table 5.5.4).

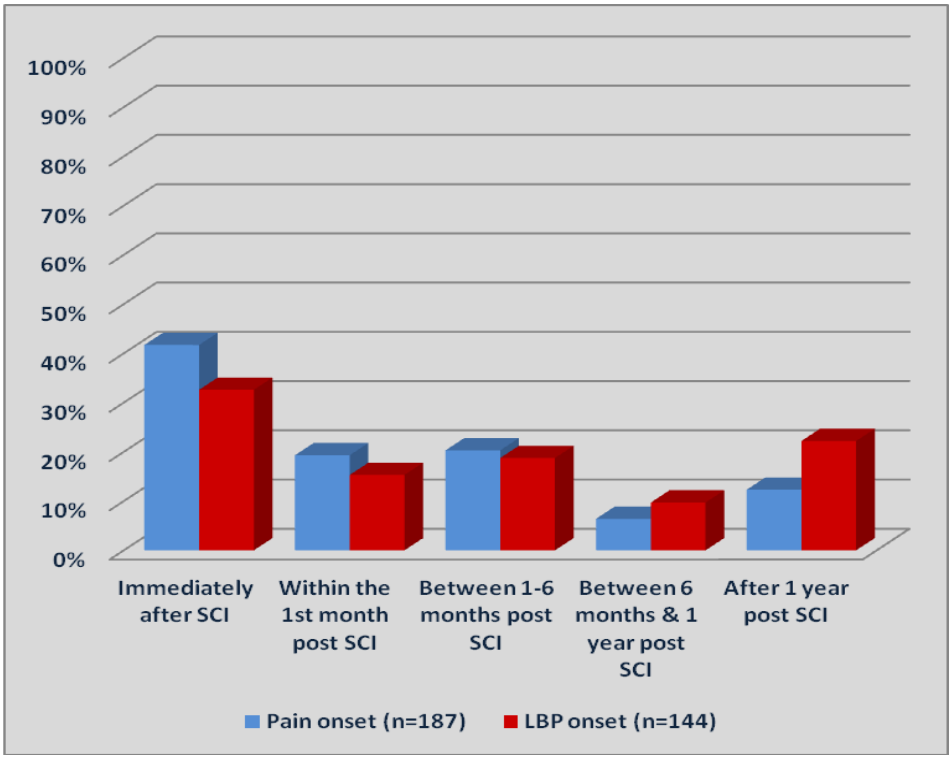

Figure 6.1.4: Percentage of people reporting time of pain and LBP onset post iSCI.
Abbreviations: iSCI, Incomplete Spinal Cord Injury; LBP, Low Back Pain.

As part of the second hypothesis theme it was hypothesised that:

Hypothesis 0 (null): In people with iSCI there is no significant correlation between pain or LBP onset post iSCI and the number of pain or LBP days felt in a month.

Hypothesis 4a: In people with iSCI there is a significant correlation between pain onset post iSCI and the number of pain days felt in a month.

Hypothesis 4b: In people with iSCI there is a significant correlation between LBP onset post iSCI and the number of LBP days felt in a month.

The gamma test (γ) which assesses correlations between variables on an ordinal level was used. Among people with pain, the correlation between pain onset and pain days was negative and statistically significant, thus the earlier the onset of pain, the more the pain days felt in the month (γ=-0.27, p=0.003, n=186, gamma test). The same was found in the case of LBP onset post iSCI and LBP days felt in a month where the correlation was slightly stronger (γ=-0.29, p=0.002, n=137, gamma test).

The only study in the literature to have discussed LBP onset post SCI[371] found that 87.5% of people with LBP reported LBP onset immediately post injury. In that study, people had a traumatic onset to their SCI and thus, to check if the findings of the current study would match the findings of Raissi et al,[371] LBP onset was examined per cause of injury. Time of LBP onset post iSCI was divided into two groups: immediately after iSCI, and any other time. Only a 28.2% of people with a traumatic injury reported a LBP onset immediately post injury, which differs substantially from Raissi et al.[371] A higher proportion of people with a non-traumatic injury (42.6%) reported an immediate LBP onset following iSCI (Table 6.1.5).

Table 6.1.5: Time of LBP onset post iSCI reported by people divided into groups by cause of injury. Differences in reported time of LBP onset.

	LBP onset immediately after iSCI	Statistical Test	LBP onset any time later	Statistical Test
Traumatic injury	28.4% n=27		42.6% n=20	
Non traumatic injury	42.6% n=19	χ^2=1.04 p=0.30	57.4% n=12	χ^2=17.69 **p≤0.001*** **

***Significant at p≤0.001 level.

Statistical tests: χ^2, Pearson's Chi-Square.

Part 2; Pain extent and LBP experience

6.2.1 Introduction

The previous section of this chapter answered the first part of the study's main research question about the presence of LBP in people with iSCI. This part of the chapter will explore the experience of pain focusing further on LBP. The experience of pain is divided in: 1) pain extent, 2) pain quality and 3) pain intensity. Quality and intensity of pain will focus on LBP.

To remind the reader, data on LBP quality was collected via the PRI of the SF-MPQ. Data on LBP intensity was collected via the PPI of the SF-MPQ and a 0-10 NRS. Finally, data to examine pain extent was collected via the body chart.[23] Of the 219 respondents to this study, 200 reported having pain all of whom were asked to complete the body chart. Of the 200 people with pain, 161 reported having LBP and were asked to report on the quality and intensity of their LBP.

6.2.2 Bonferroni correction

In the current part of the analysis the number of multiple tests done on all the variables of interest was the same (n=13) thus the α-level of statistical significance set by Bonferroni was p≤0.0038 (Appendix 6: Table 6.1.1).

6.2.3 Pain extent; general results

The body chart was initially divided into 45 areas as discussed by Margolis et al.[282] Then these 45 areas were grouped into eight broader areas; 1) head, 2) neck and shoulders, 3) upper extremities, 4) front torso and genitals, 5) back, 6) buttocks, 7) thighs and 8) legs and feet. This grouping was reported in the study of Widerström-

[23] For detail on the SF-MPQ see Chapter 5, Section 5.9.1

Noga et al[488] and has been recommended by the ISCIPDS:B.[483] According to ISCIPDS:B,[483] further divisions to allow for more precise locations can be made, thus the back was divided into upper and lower area totalling 9 areas on the body chart (Figure 6.2.1).

ISCIPDS:B[483] encourages the division of some body areas, including the back, to right side, midline and left side. In this study the area of the back was divided into right side, left side and midline and the midline was defined as the line that included the spine and only a few centimetres around it. To ensure that this area was consistently measured in all respondents, data from the body charts were collected using a quadrille formatted screen.

Using the instructions of the MPQ, respondents had to indicate if pain was "internal", "external" or both. Some respondents failed to do this or they described pain using their own words. Notes were made accordingly. Of the 200 people who reported having pain, 10 did not complete the body chart at all leaving a group of 190 people suitable for analysis.

There were occasions where the respondents had specified that they had pain in a particular area on their body but failed to mark this area on the body chart. This was corrected as appropriate whenever possible.

The mean number of areas with pain based on the 45-area division (n=190) was 7.82±7.03 (mean±SD) (Appendix 6, Figure 6.2.1). The mean number of areas with pain based on the 8-area division was 3.2±1.5 (mean±SD). Data from the 9-area division were used to examine differences or relationships between pain extent and other variables of interest. The mean number of areas with pain using the 9-area division was 3.3±1.7 (mean±SD). The most frequently reported area with pain was the lower back followed by the thighs and then the legs and feet (Table 6.2.1, Figure 6.2.2).

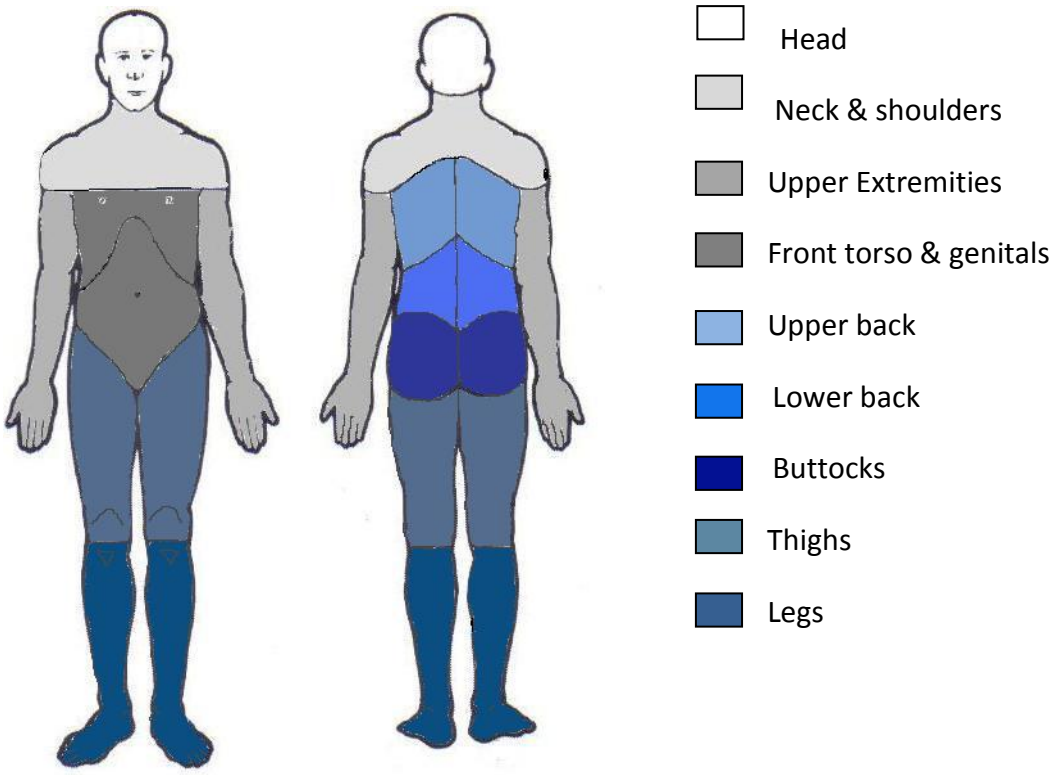

Figure 6.2.1: Body chart divided into 9 areas (based on the 8 body-areas by Widestrom -Noga et al[488])

A quarter of the respondents (24.7%) reported having two areas with pain on their bodies, closely followed by people with 3 pain areas (21.1%) (Appendix 6, Figure 6.2.2).

In the upper back area, pain most commonly occurred at the left side (19%) and in the lower back area it mainly occurred in the midline (57.6%). When pain was at the buttocks, the midline area (defined as the area to include the anus) was the most common location for pain (34.7%) (Table 6.2.1).

Finally, referring to the back area, pain was more frequently reported as "internal" followed by the combination of "both internal and external" pain. This was more the case for the midline area of the upper back and for all areas of lower back pain (Appendix 6, Table 6.2.1).

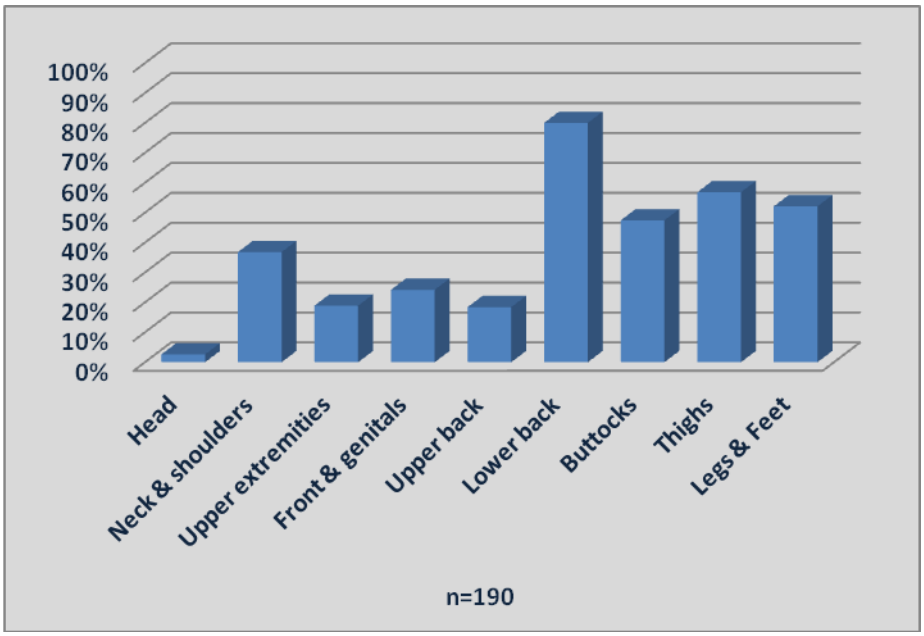

Figure 6.2.2: Percentage of people reporting pain per body areas.

Table 6.2.1: Percentage of people reporting pain at the back and buttocks

Pain on back area and buttocks[¥]	n (total n=190)	Percentage of people with pain (%) (total n=190)
Back area	161	84.7
Upper back right side	21	11.0
Upper back left side	19	10.0
Upper back midline	34	18.0
Lower back right side	45[1]	34.1
Lower back left side	47[1]	35.5
Lower back midline	76[1]	57.6
Buttocks	107	56.3
Right buttock	58	30.5
Left buttock	59	31.0
Midline area buttock (including anus)	66	34.7

[1]Total responses in this case were n=132, [¥]using 9-areas division

6.2.4 Pain extent; relation to LBP and MSKP

As expected, the mean number of areas with pain was larger for people with LBP compared to those without and a significant difference between the groups was found for all time points of LBP (Table 6.2.3). It was also found that among people with pain,

those with MSKP (n=83) reported significantly higher mean number of areas with pain than those without MSKP (n=112) (p≤0.001, Mann-Whitney U test).

Table 6.2.3: Mean number of areas with pain in groups by pain presence. Differences between groups

	Yes mean±SD, median, min-max, n	**No** mean±SD, median, min-max, n	**Statistical test**
Lifetime LBP	3.7±1.6 4, 1-9 n=161	1.9±0.9 2, 1-5 n=39	U=995.5 **p≤0.001*** **
Current LBP	3.7±1.7 1-9 n=144	2.3±1.3 2, 1-6 n=49	U=1672.5 **p≤0.001*** **
LBP over last 1 month	3.7±1.7 4, 1-9 n=145	2.2±1.3 2, 1-6 n=48	U=1595 **p≤0.001*** **
LBP over last 3 months	2.1±1.3 4, 1-6 n=148	3.7±1.7 4, 1-9 n=44	U=1390.5 **p≤0.001*** **
MSKP[1]	4.0±1.7 4, 1-8, n=83	2.8±1.3 3, 1-7, n=112	U=2546.5 **p≤0.001*** **

[1]Three outliers eliminated; ***Significant at p≤0.001 level; **in bold:** significant following application of the Bonferroni correction.
Abbreviations: LBP, Low Back Pain; MSKP, Musculoskeletal Pain.
Statistical test: Mann-Whitney U test.

6.2.5 Pain extent; relation to demographic profile characteristics

People who completed the body chart were compared for differences or correlations in their demographic profile characteristics; sex, cause of injury, age, type of injury and time since injury. Females reported significantly more areas with pain than males: 3.8±1.6 versus 2.9±2.4, p≤0.001, (t=-3.68, 95% CI -1.32, -0.40, independent t-test) (Table 6.2.4). No other significant differences or correlations were found between the number of areas with pain and the participants' demographic profile characteristics (Table 6.2.4, Appendix 6: Table 6.3.1 and Figures 6.3.1-6.3.3).

Table 6.2.4: Mean number of areas with pain in groups by demographic profile characteristics. Differences and correlations between groups.

Demographic	**Number areas of pain** (range 1-9) mean±SD, n	**Statistical Tests**
Sex[1]		t=-3.68
Male	2.9±2.4, n=118	**p≤0.001*** **
Female	3.8±1.6, n=70	95% CI -1.32, -0.40
Cause of Injury[2]		t=-0.43
Traumatic	3.2±1.5, n=131	p=0.66
Non-traumatic	3.3±1.5, n=59	95% CI -0.10, 0.24
Age		r=-0.46
		p=0.54, n=211
Type of injury		t=-0.57
Tetraplegia	3.3±1.9, n=84	p=0.56
Paraplegia	3.4±1.5, n=106	95% CI -0.64, 0.35
Time since injury		r=0.08
		p=0.22, n=218

[1]Three outliers were eliminated, [2]Four outliers were eliminated; ***Significant at p≤0.001 level; **in bold:** significant following application of the Bonferroni correction.
Statistical tests: t, independent t-test; r, Pearson's correlation.

As it was found that females reported significantly more mean number of areas with pain than males gender was examined further. It was found that for both males but also females, people with LBP (all time periods) or MSKP reported more mean numbers of areas with pain compared to those without LBP maintaining significance post Bonferroni application in most cases (Table 6.2.5).

Table 6.2.5: Mean number of areas with pain in groups with or without LBP or MSKP

	Males			Females		
LBP or MSKP presence	**Yes** mean±SD, median, min-max, n	**No** mean±SD, median, min-max, n	**Statistical Test**	**Yes** mean±SD, median, min-max, n	**No** mean±SD, median, min-max, n	**Statistical Test**
Lifetime LBP	3.5±1.6 3, 1-9 n=90	1.6±0.7 1.5, 1-3 n=26	U=334.0[1] **p≤0.001*** **	4.1±1.6 4, 1-8 n=59	2.2±0.9 2.5, 2-5 n=10	t=-3.63, df67[2] p=0.01 95% CI -2.94, -0.85 U=92.5 **p≤0.001*** **
Current LBP	3.3±1.4 3, 1-6 n=81	1.7±0.8 2, 1-6 n=29	U=402.0[3] **p≤0.001*** **	4.1±1.6 4, 1-8 n=54	2.5±0.9 4, 1-8 n=13	t=-3.43, df65[4] p=0.01 95% CI -2.58, -0.68 U=144.5 **p≤0.001*** **
LBP over last 1 month	3.5±1.6 2, 1-6 n=82	2.1±1.2 2, 1-6 n=34	U=646.0 **p≤0.001*** **	4.0±1.6 4, 1-8 n=56	2.3±1.0 3, 1-4 n=11	t=-3.31, df65[4] p=0.02[5] 95% CI -2.70, -0.67
LBP over last 3 months	3.3±1.4 3, 1-6 n=82	1.8±0.9 2, 1-4 n=30	U=489.0 **p≤0.001*** **	4.0±1.6 4, 1-8 n=57	2.2±0.9 2.5, 1-3 n=10	t=-3.55, df65[1] p≤0.01[5] 95% CI -2.92, -0.81
MSKP	3.6±1.8 3, 1- n=43	2.8±1.4 2, 1-91 n=74	t=-2.9, df115 **p≤0.001*** ** 95% CI -1.4, -0.2	4.6±1.7 3, 2-9 n=38	3.0±1.4 3, 1-7 n=31	t=-4.05, df67 **p≤0.001*** ** 95% CI -2.3, -0.7

[1]Two outliers eliminated, [2]One outliers eliminated, [3]Six outliers eliminated, [4]Three outliers eliminated; ***Significant at p≤0.001 level, **in bold:** significant following application of the Bonferroni correction; [5]not significant post Bonferroni correction

Abbreviations: LBP, Low Back Pain; MSKP, Musculoskeletal Pain. *Statistical tests*: U, Mann-Whitney U test; t, independent t-test.

6.2.6 Pain extent; pain/LBP days, free periods, onset

Analysis showed that the more areas with pain felt on the body, the more the days of pain or LBP felt per month ($p \leq 0.01$, $\rho=0.33$, $n=182$ and $p=0.004$, $\rho=0.24$, $n=143$, Spearman's correlation) but these correlations were not significant following application of the Bonferroni correction, though for LBP days it was very near significance (Figure 6.2.4, Appendix 6: Table 6.4.1).

In addition, it was found that the more the number of areas with pain, the less frequent the number of pain-free weeks ($p \leq 0.001$, $\rho=0.25$, $n=170$, Spearman's correlation) (Figure 6.2.4; Appendix 6: Table 6.4.2). This similar positive correlation did not pass the Bonferroni α-level in the case of LBP free weeks ($p=0.009$, $\rho=0.25$, $n=110$, Spearman's correlation) (Figure 6.2.5, Appendix 6: Table 6.4.2).

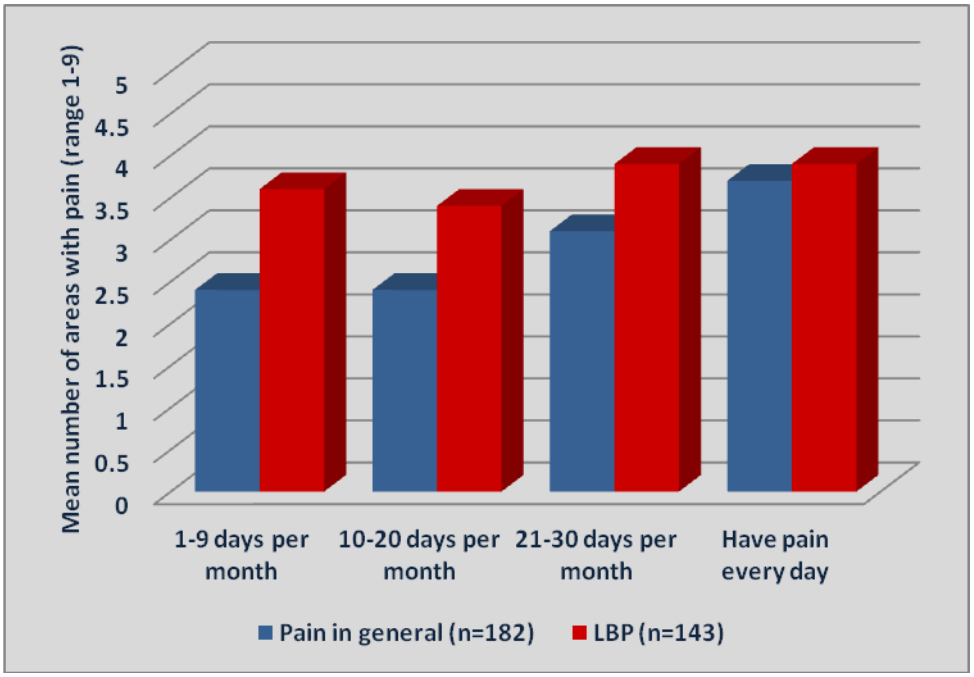

Figure 6.2.4: Mean number of areas with pain in groups divided by pain/LBP days felt per month.
Abbreviations: LBP, Low Back Pain.

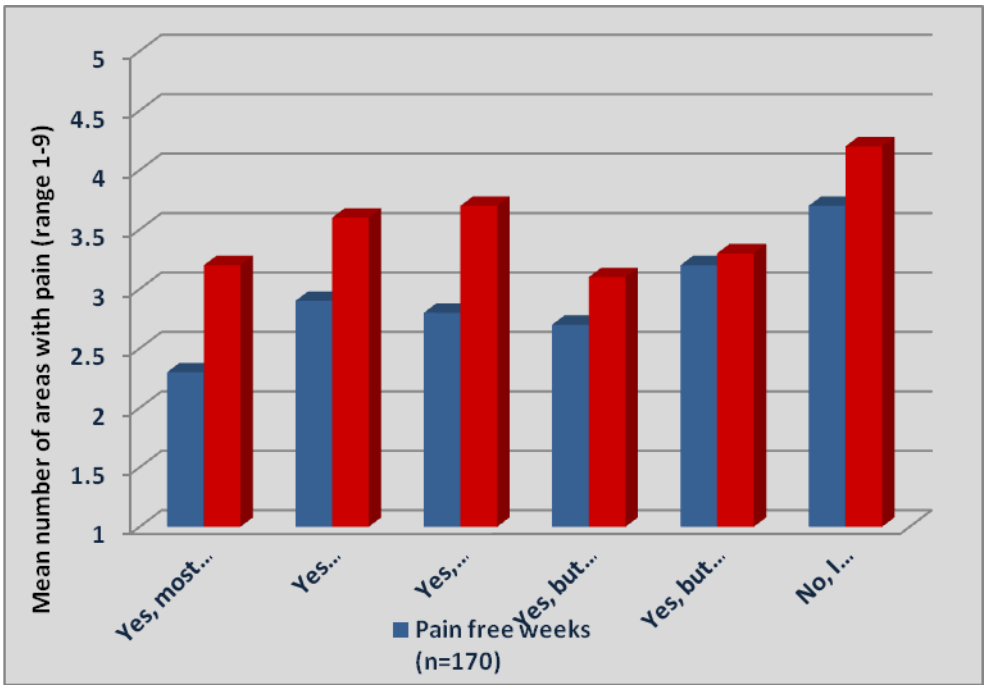

Figure 6.2.5: Mean number of areas with pain in groups divided by frequency of pain/LBP free weeks.
Abbreviations: LBP, Low Back Pain.

As part of the second hypothesis theme, which related to the onset of pain/LBP, it was hypothesised that:

Hypothesis 0 (null): In people with iSCI there is no significant correlation between the number of areas with pain and the onset of pain or LBP post iSCI.

Hypothesis 5-pain: In people with iSCI there is a significant correlation between the number of areas with pain and the onset of pain post iSCI.

Hypothesis 5-LBP: In people with iSCI there is a significant correlation between the number of areas with pain and the onset of LBP post iSCI.

Following application of the Bonferroni correction, no significant correlation was found in the case of pain onset (p=0.042, ρ=-0.15, n=187, Spearman's correlation, 95%CI -0.28, -0.02) (Figure 6.2.6; Appendix 6: Table 6.4.3) or LBP onset (p=0.34, ρ=-0.08, n=135, Spearman's correlation, 95%CI -0.23, 0.07) (Figure 6.2.6; Appendix 6: Table 6.4.3). The strength of the correlations was weak and the 95% CI wide. Consequently, the null hypothesis cannot be rejected.

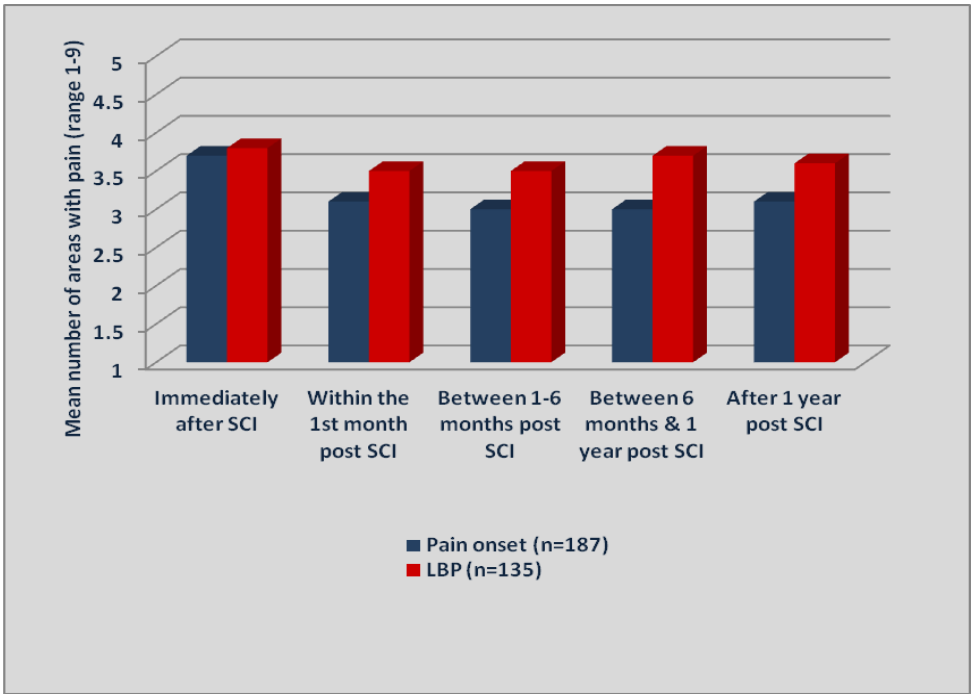

Table 6.2.6: Mean number of areas with pain in groups divided by time of pain or LBP onset post iSCI.
Abbreviations: LBP, Low Back Pain; iSCI, incomplete Spinal Cord Injury.

6.2.7 LBP quality and intensity; general results

The PRI, which measures quality, consists of 15 word descriptors that are given a numerical value on an ordinal scale 0-3[24].[303,304] The rank value of each person's response was added to give the sum of the rank values for the person. Then the totals of all respondents were added to give the sum for PRI for the group. Three pain scores derive from the sum of the PRI of the rank values of the chosen words; 1) sensory (first 11 descriptors), 2) affective (following 4 descriptors) and 3) total PRI (all descriptors)[303] (see also Chapter 5: Section 5.9.1).

The second part of the SF-MPQ consisted of a 10cm long horizontal VAS with end points of "no pain" to "worst pain imaginable". In the present study participants were asked to mark their intensity of current LBP as well as their usual LBP intensity over the

[24]Each word is rated on an intensity scale 0=none, 1=mild, 2=moderate or 3=severe and this is the rank value of the word.

last 1 and last 3 months. Unpredicted technical difficulties at the time of designing the web format of the survey did not allow for the use of the VAS online. To solve this problem, it was decided that the web survey would include a NRS instead of the VAS. However, the paper version of the questionnaire was prepared and already included the VAS. The NRS was chosen because, like the VAS, it is a unidimensional scale and like the VAS it is extensively used in pain assessment.[269] Also there is a good correlation between the NRS and the VAS.[101,373] The NRS has been preferred to the VAS by some patients.[493] Because the two survey formats were going to end up using two (similar in their psychometric qualities) different tools to measure LBP intensity, an effort was made to "match" the two scales as much as possible. The NRS was designed to be 10cm long and have the same end points as the VAS. The aim was to enable pooling of the data collected from the two tools together and analysing it.

The last part of the SF-MPQ consisted of an overall PPI score measured on a 6-point verbal rating scale (VRS) ("no pain" to " excruciating pain") which were given numeric values (0 – 5).

People used all 15 descriptors to portray the quality of their LBP. The less frequently used descriptor was "splitting" (29.9%) and the most frequently used was "aching" (76.2%) "Aching" was ranked mainly as of moderate intensity (by 36.4% of respondents), followed by "tiring-exhausting" (61.6%) which was also rated mainly as of moderate intensity (by 26.5% of respondents) (Table 6.2.6). The total PRI was 13.6±10.8 (mean±SD), the sensory PRI was 10.2±7.8 (mean±SD) and the affective PRI was 3.4±3.5 (mean±SD) (Appendix 6, Table 6.5.1). The number of words chosen ranged from 1 to 15 and the mean was 7.05±4.1 (mean±SD). Some of the respondents (6.4%) used all 15 descriptors to describe their LBP. Among the 11 descriptors for the sensory dimension people chose a mean of 5.3±3.5 (mean±SD, range 0-11) and 0.9% did not choose any sensory descriptor but 8.2% used all of them. Finally, from the 4 possible descriptors for the affective dimension, people used a mean of 0.7±1.55 (mean±SD, 0-4 range), 21.9% of respondents did not choose any affective descriptor and 15.6% used all of them.

Table 6.2.6: Percentage of people reporting each LBP descriptor

Pain descriptors	n	Reported pain total	None	Mild	Moderate	Severe
Throbbing	149	40.9	59.1	16.1	13.4	11.4
Shooting	151	47	53	15.9	17.2	13.9
Stabbing	149	45.6	54.4	10.1	16.1	19.5
Sharp	150	54	46	14	21.3	18.7
Cramping	150	47.3	52.7	22.7	18	6.7
Gnawing	152	55.3	44.7	21.7	23.7	9.9
Hot-burning	149	53.7	46.3	18.8	19.5	15.4
Aching	151	76.2	23.8	18.5	36.4	21.2
Heavy	150	44.7	55.3	16	18.7	10
Tender	150	43.3	56.7	15.3	17.3	10.7
Splitting	147	29.9	70.1	13.6	10.2	6.1
Tiring-exhausting	151	61.6	38.4	13.9	26.5	21.2
Sickening	150	35.3	64.7	15.3	10	10
Fearful	151	31.1	68.9	13.9	9.9	7.3
Punishing-cruel	152	46.7	53.3	17.8	16.4	12.5

Data collected about the intensity of LBP via the NRS and the VAS were compared to ensure that data from both groups did not differ significantly thus could be pooled and analysed together. A significant difference was found in the mean intensity of LBP over the last 1 month (p=0.004, t=2.95, 95% CI 5.06, 25.43, independent t-test) and the last 3 months (p=0.002, t=3.13, 95% CI 5.92, 26.06, independent t-test) between people using the NRS (n=122) and those using the VAS (n=31). The difference was not statistically significant for current LBP (p=0.07, t=1.8, 95% CI -0.90, 20.0, independent t-test). A minimum clinically significant difference (MCSD) for chronic LBP is said to be 20mm when using the VAS and 2.5 points when using the NRS (or 25mm if a 0-100 NRS is used).[345] Even though the MCSD is typically used in interventional studies to identify a meaningful change in the score, which is not the aim of this study, it was noticed that the difference in the mean intensity measured by NRS and VAS was greater than the recommended MCSD levels (47.0±2.7 for NRS versus 31.8±20.7 for VAS) (Table 6.2.7; Appendix 6, Section 6.2.1).

A brief analysis to identify possible reasons for the observed differences in the mean scores of people using the NRS and the VAS showed some differences in the mean scores of the Greek group (using the VAS) to the UK and USA groups (using the NRS) for LBP intensity over the last 1 and 3 months. This finding implied that country of

residency could have been a factor affecting the results. The respondents who completed the VAS mainly had a non-traumatic cause to their injury but further analysis did not reveal that the cause of injury was the reason for the finding. This brief analysis did not clarify the reasons for the observed differences; therefore further analysis would have been needed to identify the exact factors to affect the results. But, this was beyond the aim of the study. It was decided that it would have been inappropriate to pool together and analyse the above data. Consequently only the data collected using the NRS, which was the larger of the two groups, were included in the analysis."

Table 6.2.7: Mean difference of LBP intensity between people using the NRS and the VAS measures

	Mean±SD, min-max NRS (n=122), VAS (n=32)	**Statistical Tests**
PPI – current (range 0-100)	NRS: 47.0±27.1, 0.0 – 100 VAS: 31.8±20.7, 0.0 – 84.0	t=1.8, df152 p=0.07 95% CI -0.90, 20.0
PPI – over last 1 month (range 0-100)	NRS: 47.1±27.1, 0.0 – 98.0 VAS: 31.8±20.7, 1.25 – 78.5	t=2.95, df152 **p=0.004**** 95% CI 5.06, 25.43
PPI – over last 3 months (range 0-100)	NRS[1]: 47.9±26.9, 0.0 - 100 VAS: 31.9±20.1, 1.0 – 81.5	t=3.13, df151 **p=0.002**** 95% CI 5.92, 26.06

[1] In this case n=121, **Significant at p≤0.01 level.
Abbreviations: PPI, Present Pain Intensity; NRS, Numeric Rating Scale; VAS, Visual Analogue Scale.
Statistical tests: t, independent t-test.

The mean intensity of current LBP was 42.6±28.3 (mean±SD), usual LBP intensity over the last month was 47.0±27.1 (mean±SD), and usual LBP intensity over the last 3 months was 47.9±269 (mean±SD). Most people rated their evaluative overall intensity of LBP as discomforting (41.5%), followed by distressing (26.5%) and then mild (18.4%) (Figure 6.2.7). The mean intensity on the PPI was 2.4±1.0 (mean±SD).

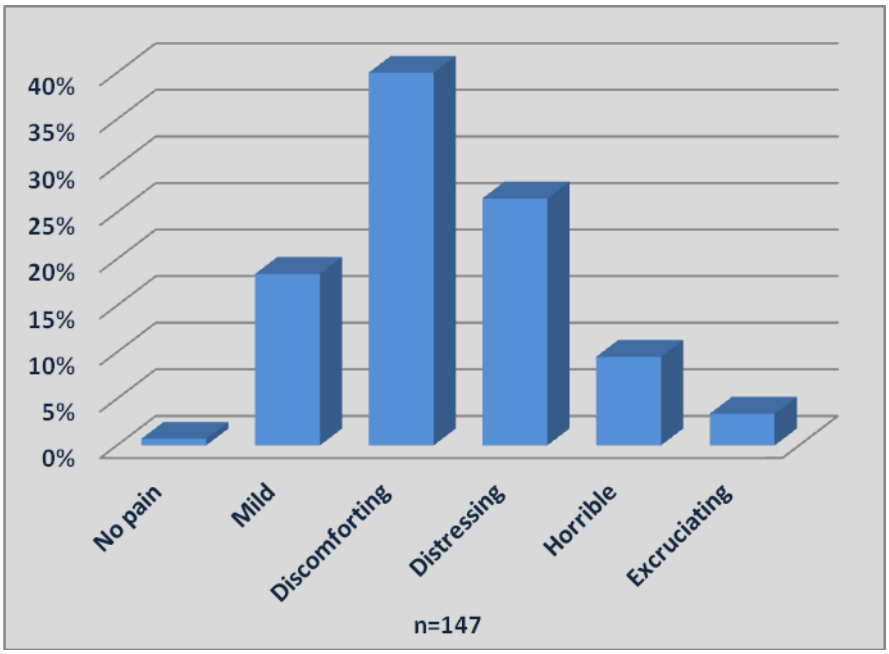

Figure 6.2.7: Percentage of people reporting their evaluative overall intensity of LBP

6.2.8 LBP quality and intensity; relation to demographic profile characteristics

The quality and the intensity of LBP were examined for differences or correlations according to the respondents' demographic profiles; sex, cause of injury, age, level of injury and time since injury.

Men (n=88) and women (n=62) described their LBP very similarly for both sensory and affective dimension of the PRI and no significant differences were found in their quality scores (Appendix 6: Table 6.5.2). The intensity of LBP in men (n=76) was slightly higher than in women (n=46) for reported current LBP but not for LBP over the last 1 and 3 months (Appendix 6: Table 6.5.2). The mean intensity was moderate for all three time periods and in no case statistically significant between the two sexes. Similarly, males (n=80) and females (n=59) reported the same evaluative PPI for their LBP and no significant difference existed between the two sexes (Appendix 6: Table 6.5.2).

People with a traumatic (n=100) and non-traumatic (n=52) cause for their injury described the quality of their LBP similarly (Appendix 6: Table 6.5.3). People with a non-traumatic cause reported slightly higher mean intensity for current LBP, LBP over

the last 1 month , 3 months and evaluative PPI but not enough to reach a significant difference (Appendix 6: Table 6.5.3, Figures 6.5.4-6.5.6)

Interestingly, it was found that as the age of the participants increased, their total PRI improved significantly ($p \leq 0.001$, $r=-0.27$, $n=148$, Pearson's correlation). The correlation between age and sensory component had the same direction and was singificant ($p=0.002$, $r=-0.25$, Pearson's correlation, $n=148$). The correlation between age and the affective component of PRI was weak and non-significant ($r=-0.14$, $p=0.08$, Pearson's correlation). Age related weakly to LBP intensity and the correlations were not significant; with intensity for current LBP: $p=0.60$, ($r=0.09$, $n=117$, Pearson's correlation); with LBP intensity over the last 1 month: $p=0.41$, ($r=0.07$, $n=117$, Pearson's correlation); with LBP intensity over the last 3 months: $p=0.56$, ($r=0.05$, $n=117$, Pearson's correlation); and with evaluative PPI of LBP: $p=0.51$, ($r=-0.05$, $n=142$, Pearson's correlation).

People with paraplegia (n=92) reported higher, therefore worse, quality for their LBP compared to people with tetraplegia (n=58) which was significant for the sensory and affective dimensions (Table 6.2.8). They also reported worse intensity of LBP (all time points) but the differences did not reach significant levels (Table 6.2.8). Further analysis on the three levels of injury showed that overall, people with a thoracic injury reported worse quality of LBP (PRI) while those with a lumbar injury reported worse intensity of LBP (Appendix 6: Tables 6.5.4, 6.5.5 and Figures 6.5.7–6.5.9).

Table 6.2.8: Mean LBP quality and intensity in groups divided by type of injury and between groups differences

	Tetraplegia mean±SD, min-max	**Paraplegia** mean±SD, min-max	**Statistical Tests**
S-PRI (range 0-33)	7.24±5.4, 0-21, n=58[1]	11.5±7.9, 1-30, n=92	t=-3.6, df148 **p≤0.001*** ** 95% CI -6.6, 1.9 U=1845, **p≤0.001*** **
A-PRI (range 0-12)	2.5±2.9, 0-11 n=58[1]	3.7±3.6, 0-12 n=92	t=-2.23, df148 p=0.02[3] 95% CI -2.4, 0.1
PRI total (range 0-45)	9.1±7.1, 1-29 n=56[2]	14.7±10.4, 1-39 n=94	t=-3.58, df144 **p≤0.001*** ** 95% CI -8.75, -2.5 U=1741.5, **p=0.002****
Intensity for current LBP (range 0-100)	37.8±25.6, n=60 0-97	42.3±28.7, n=94 0-100	t=-0.99, df152 p=0.32, 95% CI -13.5, 4.5
Intensity for LBP over last 1 month (range 0-100)	41.0±26.2 0-98, n=60	45.7±26.8 0-95, n=94	t=-1.09, df152 p=0.27, 95% CI -13.5, 18.9
Intensity for LBP over last 3 months (range 0-100)	40.2±27.1 0-95, n=60	47.4±25.7 0-100, n=93	t=-1.66, df151 p=0.09, 95% CI =15.8, 1.4
PPI evaluative for LBP[1] (range 0-5)	2.2±1.0 1-5, n=58	2.4±0.8 1-4, n=83	t= -0.97, df139 p=0.33, 95% CI -0.46, 0.15

[1]2 outliers were eliminated, [2]3 outliers eliminated, **Significant at p≤0.01 level, ***Significant at p≤0.001 level; **in bold:** significant following application of the Bonferroni correction; [3]not significant post Bonferroni correction

Abbreviations: PRI, Pain Rating Index; S-PRI, Sensory PRI; A-PRI, Affective PRI; PPI, Present Pain Intensity; LBP, Low Back Pain. *Statistical tests*: t, independent t-test; U, Mann-Whitney U test.

The correlations between time since injury and quality of LBP were positive but weak and not significant; with the sensory dimension of PRI: p=0.078, (ρ=0.144, Spearman's correlation, n=151); with the affective dimension of PRI: p=0.693, (ρ=0.031, Spearman's correlation, n=151); and with the total PRI: p=0.078, (ρ=0.144, Spearman's correlation, n=151). The same was found between time since injury and intensity of LBP; with intensity of current LBP: p=0.25, (r=0.10, Pearson's correlation, n=121); with intensity of usual LBP over the last 1 month: p=0.34, (r=0.086, Pearson's correlation, n=121); with intensity of last 3 months: p=0.34, (r=0.086, Pearson's correlation, n=120); and with evaluative PPI: p=0.51, (r=0.054, Pearson's correlation, n=146).

6.2.9 LBP quality and intensity; pain/LBP days, free period, onset

As the reported number of LBP days felt per month increased, the quality of LBP got worse and in all cases the strength of the correlations were moderate and highly significant; between the number of LBP days and: the sensory dimension of PRI: p≤0.001, (ρ=0.44, Spearman's correlation, n=147); for the affective dimension of PRI: p≤0.001, (ρ=0.33, n=146, Spearman's correlation); for total PRI: p≤0.001, (ρ=0.39, Spearman's correlation, n=144) (Table 6.2.9). The increase of pain days felt in a month did not correlate significantly with the quality of LBP though the direction of the correlations were the same but they were weak (Appendix 6: Table 6.6.1).

Similarly, as the number of LBP days felt in the month increased so did the intensity of LBP and correlations were highly significant; for reported intensity of current LBP: p≤0.001, (ρ=0.59, Spearman's correlation, n=119); for reported LBP intensity over the last month: p≤0.001, (ρ=0.55, Spearman's correlation, n=117); for intensity over last 3 months: p≤0.001, (ρ=0.45, Spearman's correlation, n=116); and for evaluative PPI: p≤0.001, (ρ=0.45, Spearman's correlation, n=136) (Table 6.2.9, Appendix 6: Figure 6.6.1). The correlation between increasing number of pain days and intensity of LBP had the same positive direction, it was often of low moderate strength but not statistically significant (Appendix 6: Table 6.6.1).

Table 6.2.9: Mean LBP quality and intensity in groups by number of LBP days per month. Correlations between groups

Number of LBP days per month	S-PRI (range 0-33) mean±SD, min-max	A-PRI (range 0-12) mean±SD, min-max	Total PRI (range 0-45) mean±SD, min-max	Intensity of current LBP (range 0-100) mean±SD, min-max	Intensity of LBP over last 1 month (range 0-100) mean±SD, min-max	Intensity of LBP over last 3 months (range 0-100) mean±SD, min-max	Evaluative overall intensity of LBP (range 0-5) mean±SD, min-max
1-9 days	6.2±4.7 1-17, n=37[1]	1.9±2.2 0-7, n=36[1]	8.8±7.3 1-28, n=37	19.2±20.2 0-70, n=27	21.3±20.4 0-67, n=26	25.0±22.5 0-72, n=25	1.7±0.7 0-3, n=37
10-20 days	4.8±2.2 2-10, n=22[2]	1.8±2.1 0-7, n=25	6.1±4.1 2-19[3], n=25	24.4±18.5 0-65, n=15	31.8±21.4 2-75, n=15	34.3±21.6 2-85, n=15	2.1±0.9 1-4, n=25
21-30 days	9.9±6.1 2-21, n=17	4.4±4.3 0-12, n=17	14.3±9.6 2-33, n=17	49.8±25.0 10-90, n=13	52.3±18.9 24-85, n=12	53.0±20.3 25-85, n=12	2.6±0.6 2-4, n=16
Every day	13.9±8.7 0-33, n=68	4.5±3.8 0-12, n=68	17.4±11.2 2-41, n=65	56.1±23.7 1-100, n=64	458.9±22.2 5-98, n=64	57.0±24.5 7-100, n=64	2.7±0.9 1-5, n=58
Statistical Test	ρ=0.44 n=147 **p≤0.001*** **	ρ=0.33 n=146 **p≤0.001*** **	ρ=0.39 n=144 **p≤0.001*** **	ρ=0.59 n=119 **p≤0.001*** **	ρ=0.60 n=117 **p≤0.001*** **	ρ=0.51 n=116 **p≤0.001*** **	ρ=0.50 n=136 **p≤0.001*** **

[1]One outlier, [2]Three outliers, [3]Three outliers; ***Significant at p≤0.001 level, **in bold:** significant following application of the Bonferroni correction.

Abbreviations: PRI, Pain Rating Index; S-PRI, Sensory PRI; A-PRI, Affective PRI; PPI, Present Pain Intensity; LBP, Low Back Pain.

Statistical tests: ρ, Spearman's rank correlation rho.

A reduction in the regularity of the LBP-free weeks related with significantly worse quality of LBP, noticed across all dimension of PRI; with the sensory dimension: p≤0.001, (ρ=0.41, Spearman's correlation, n=116); with the affective dimension: p≤0.001, (ρ=0.31, Spearman's correlation, n=119); and with total PRI: p≤0.001, (ρ=0.40, Spearman's correlation, n=115) (Table 6.2.10). Similarly, the more infrequent the pain- free weeks, the worse the quality of LBP in correlations that were of moderate strength (Appendix 6: Table 6.6.1).

The intensity of LBP was worse when pain was more persistent as the less frequent the pain-free weeks, the higher the intensity of LBP (Appendix 6: Table 6.6.1). This was similar when the LBP-free weeks were reduced and, in this case, the strength of the correlations was high; with intensity of current LBP: p≤0.001, (ρ=0.55, Spearman's correlation, n=87); with intensity of reported LBP over the last 1 month: p≤0.001, (ρ=0.53, Spearman's correlation, n=88); with intensity of LBP over the last 3 months: p≤0.001, (ρ=0.48, Spearman's, n=88); and with evaluative PPI: p≤0.001, (ρ=0.47, Spearman's correlation, n=111) (Table 6.2.10; Appendix 6: Figure 6.6.2).

Part of the third hypothesis theme was to examine the relation between pain or LBP onset post iSCI and the quality or intensity of LBP. The hypothesis is:

Hypothesis 0 – LBP quality (null): In people with iSCI there is no significant correlation between quality (sensory, affective or total PRI) of LBP and pain or LBP onset post iSCI.

Hypothesis 8a – LBP quality: In people with iSCI there is a significant correlation between the sensory dimension of quality of LBP and pain or LBP onset post iSCI.

Hypothesis 8b – LBP quality: In people with iSCI there is a significant correlation between the affective dimension of quality of LBP and pain or LBP onset post iSCI.

Hypothesis 8c – LBP quality: In people with iSCI there is a significant correlation between the total quality of LBP and pain or LBP onset post iSCI.

Table 6.2.10: Mean LBP quality and intensity in groups by LBP-free weeks. Correlations between groups

LBP free weeks	**S-PRI** (range 0-33) mean±SD, min-max	**A-PRI** (range 0-12) mean±SD, min-max	**Total PRI** (range 0-45) mean±SD, min-max	**Intensity of current LBP** (range 0-100) mean±SD, min-max	**Intensity of LBP over last 1 month** (range 0-100) mean±SD, min-max	**Intensity of LBP over last 3 months** (range 0-100) mean±SD, min-max	**Evaluative overall intensity of LBP** (range 0-5)
Yes, most of the time	6.1±4.5 2-17, n=13[1]	1.9±2.2 0-6, n=15	7.7±6.2 2-23, n=14[1]	20.0±31.2 0-100, n=9	12.2±13.2 0-35, n=9	13.2±15.3 0-40, n=8	1.4±0.8 0-3, n=13
Yes, frequently	6.6±4.9 2-14, n=9	3.3±3.1 0-11, n=9	9.9±8.2 2-25, n=9	11.5±16.3 0-23, n=2	66.0±1.4 65-67, n=2	60.0±7.1 55-65, n=2	1.9±0.3 1-2, n=9
Yes, sometimes	6.5±4.1 2-18, n=12[1]	2.1±2.7 0-7, n=13	8.3±6.2 3-25, n=12[1]	30.0±21.5 0-58, n=7	34.1±23.4 0-71, n=7	31.6±20.8 0-65, n=7	2.4±1.0 1-4, n=13
Yes, not very often	6.5±4.5 1-15, n=11	3.4±4.0 0-11, n=11	9.8±8.0 1-24, n=11	15.0±12.3 0-25, n=4	39.6±15.2 25-65, n=5	43.0±22.8 25-80, n=5	2.2±0.8 1-3, n=10
Yes, but rarely	9.7±7.3 1-24, n=23	3.6±3.8 0-12, n=23	13.4±10.4 1-34, n=23	37.7±30.3 0-90, n=22	46.4±25.2 0-88, n=22	51.2±25.2 0-85, n=22	2.3±0.9 1-4, n=22
No, I always have pain **Statistical Test**	13.9±8.1 1-30, n=48 ρ=0.41, n=116 **p≤0.001*** **	4.8±3.6 0-12, n=48 ρ=0.31, n=119 **p≤0.001*** **	17.8±10.7 3-39, n=46 ρ=0.40, n=115 **p≤0.001*** **	58.9±20.5 19-97,n=43 ρ=0.55, n=87 **p≤0.001*** **	61.6±20.0 20-98, n=43 ρ=0.53, n=88 **p≤0.001*** **	62.1±21.1 20-100, n=43 ρ=0.48, n=87 **p≤0.001*** **	2.9±1.0 1-5, n=41 ρ=0.47, n=111 **p≤0.001*** **

[1]One outlier; ***Significant at p≤0.001 level, in bold: significant following application of the Bonferroni correction.
Abbreviations: PRI, Pain Rating Index; S-PRI, Sensory PRI; A-PRI, Affective PRI; PPI, Present Pain Intensity; LBP, Low Back Pain.
Statistical tests: ρ, Spearman's rank correlation rho.

Earlier pain onset correlated with worse LBP quality (sensory, affective dimensions and total PRI) but the relations were not statistically significant and of small strength (Appendix 6: Table 6.6.1). Earlier onset of LBP post iSCI also related with worse quality of LBP (sensory, affecting dimensions and total PRI) and though relationships were stronger they failed to maintain their significance level post application of the Bonferroni correction (Table 6.2.11). Therefore, for both pain or LBP onset post iSCI and quality of LBP the null hypothesis cannot be rejected as statistical significance is not found. The practical significance needs to be considered in the case of LBP onset post iSCI.

The next hypothesis was about the onset of pain or LBP and the intensity of LBP:

Hypothesis 0 – LBP intensity (null): In people with iSCI there is no significant correlation between intensity of LBP (current, over the last 1, last 3 months, or evaluative PPI) and pain or LBP onset post iSCI.

Hypothesis 9a – LBP intensity: In people with iSCI there is a significant correlation between intensity of current LBP and pain or LBP onset post iSCI.

Hypothesis 9b – LBP intensity: In people with iSCI there is a significant correlation between intensity of LBP over the last 1 month and pain or LBP onset post iSCI.

Hypothesis 9c – LBP intensity: In people with iSCI there is a significant correlation between intensity of LBP over the last 3 months and pain or LBP onset post iSCI.

Hypothesis 9c - intensity: In people with iSCI there is a significant correlation between evaluative overall intensity of LBP and pain or LBP onset post iSCI.

The earlier pain onset following iSCI had a weak and non-statistical correlation with LBP intensity (any time point or evaluative) (Appendix 6: Table 6.6.1). However, earlier onset of LBP following iSCI correlated with higher intensity of LBP and these relations were stronger; for reported current LBP intensity: $p \leq 0.001$, (ρ=-0.29, Spearman's correlation, 95% CI -0.42, -0.14, n=105); for reported intensity of last 1 month LBP: $p \leq 0.001$, (ρ=-0.29, Spearman's correlation, 95% CI -0.42, -0.14, n=104); and for LBP intensity over last 3 months: $p \leq 0.001$, (ρ=-0.29, Spearman's correlation, 95% CI -0.42,

-0.14, n=104). However, the relationship was not statistically significant in the case of the evaluative PPI but it had the same direction (Table 6.2.11, Figures 6.2.8, 6.2.9, 6.2.10). The null hypothesis can only be rejected for the relations between LBP onset and LBP intensity (excluding evaluative PPI).

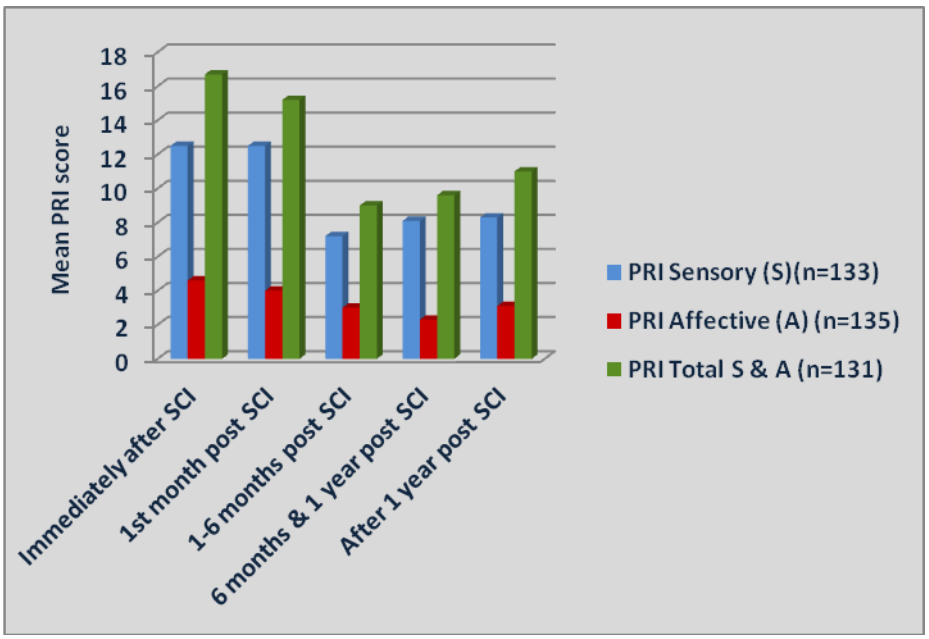

Figure 6.2.8: Mean LBP quality and intensity in groups by time of LBP onset post iSCI
Abbreviations: PRI, Pain Rating Index; PPI, Present Pain Intensity; iSCI, incomplete Spinal Cord Injury.

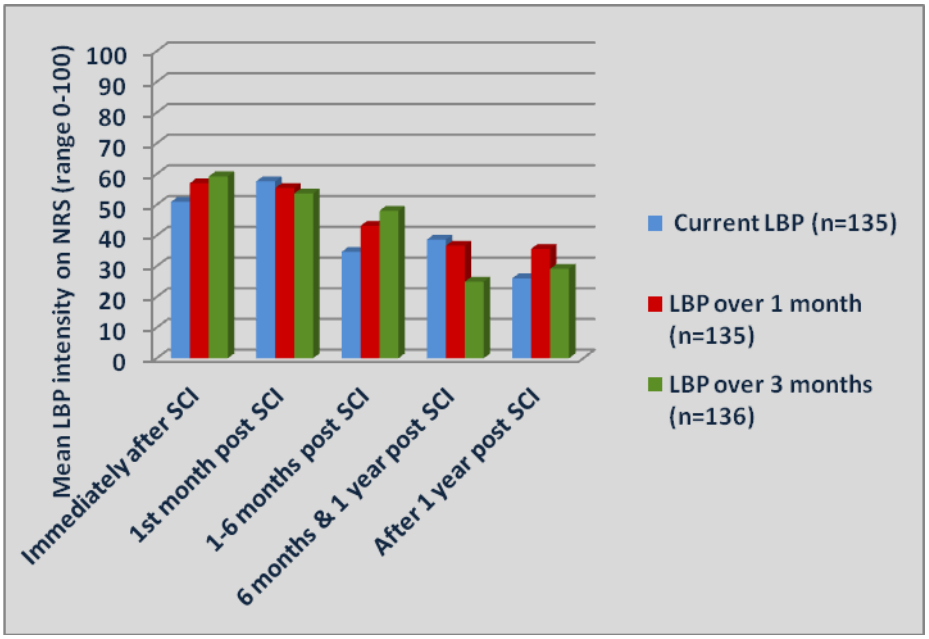

Figure 6.2.9: Mean LBP intensity in groups by time of LBP onset post iSCI
Abbreviations: NRS, Numeric Rating Scale; iSCI, incomplete Spinal Cord Injury; LBP, Low Back Pain.

Table 6.2.11: Mean LBP quality and intensity in groups by time of LBP onset post iSCI. Correlations between groups

LBP onset post iSCI	S-PRI mean±SD, min-max	A-PRI mean±SD, min-max	Total PRI mean±SD, min-max	Intensity of current LBP mean±SD, min-max	Intensity of LBP over the last 1 month mean±SD, min-max	Intensity of LBP over the last past 3 months mean±SD, min-max	Evaluative PPI mean±SD, min-max
Immediately after iSCI	12.5±7.7 0-30 n=46	4.6±4.0 0-12 n=46	16.7±10.7 1-39 n=45	48.0±30.4 0-97 n=40	52.3±27.4 0-98 n=39	54.7±25.5 1-100 n=38	2.5±1.0 1-4 n=41
Within the 1st month post iSCI	12.5±9.5 2-29 n=21	4.0±3.7 0-12 n=21	15.2±11.7 2-37 n=20	46.8±25.6 1-92 n=15	51.0±22.3 16.5-95 n=15	49.7±24.5 16-97 n=15	2.4±0.9 1-4 n=19
Between 1-6 months post iSCI	7.2±6.3 0-29 n=26	3.0±2.6 0-7 n=26	9.0±6.6 1-25 n=26	36.0±27.5 0-80 n=17	40.0±27.4 0-85 n=16	40.4±26.2 1-90 n=16	2.3±0.8 1-4 n=27
Between 6 months & 1 year post iSCI	8.1±6.2 2-23 n=14	2.3±1.9 0-5 n=14	9.6±7.6 2-28 n=14	33.8±20.6 0-74 n=8	29.2±15.0 0-52[1] n=7	36.2±23.0 0-84 n=8	2.1±0.7 1-4 n=13
After 1 year post iSCI	8.3±6.1 1-21 n=28	3.1±3.5 0-7 n=28	11.0±8.6 1-22 n=27	25.8±19.0 0-70[2] n=25	35.0±27.3 0-95 n=27	35.1±28.7 0-95 n=27	2.2±1.3 0-5 n=26
Statistical Tests	ρ=-0.23 p=0.006[3] 95%CI -0.37, -0.08 n=133[1]	ρ=-0.23 p=0.006[3] 95%CI -0.37, -0.08 n=135	ρ=-0.25 p=0.04[3] 95%CI -0.38, -0.10 n=131[2]	ρ=-0.29 **p≤0.001***** 95%CI -0.42, -0.14 n=105	ρ=-0.29 **p≤0.001***** 95%CI -0.42, -0.14 n=104	ρ=-0.29 **p≤0.001***** 95%CI -0.42, -0.14 n=104	ρ=-0.13 p=0.11 95%CI -0.28, -0.02 n=126

[1]Two outliers, [2]One outlier, [3]not significant post Bonferroni correction; *Significant at p≤0.05 level, **Significant at p≤0.01 level, ***Significant at p≤0.001 level, **in bold:** significant following application of the Bonferroni correction;
Abbreviations: PRI, Pain Rating Index; S-PRI, Sensory PRI; A-PRI, Affective PRI; PPI, Present Pain Intensity; LBP, Low Back Pain.
Statistical tests: ρ, Spearman's rank correlation rho.

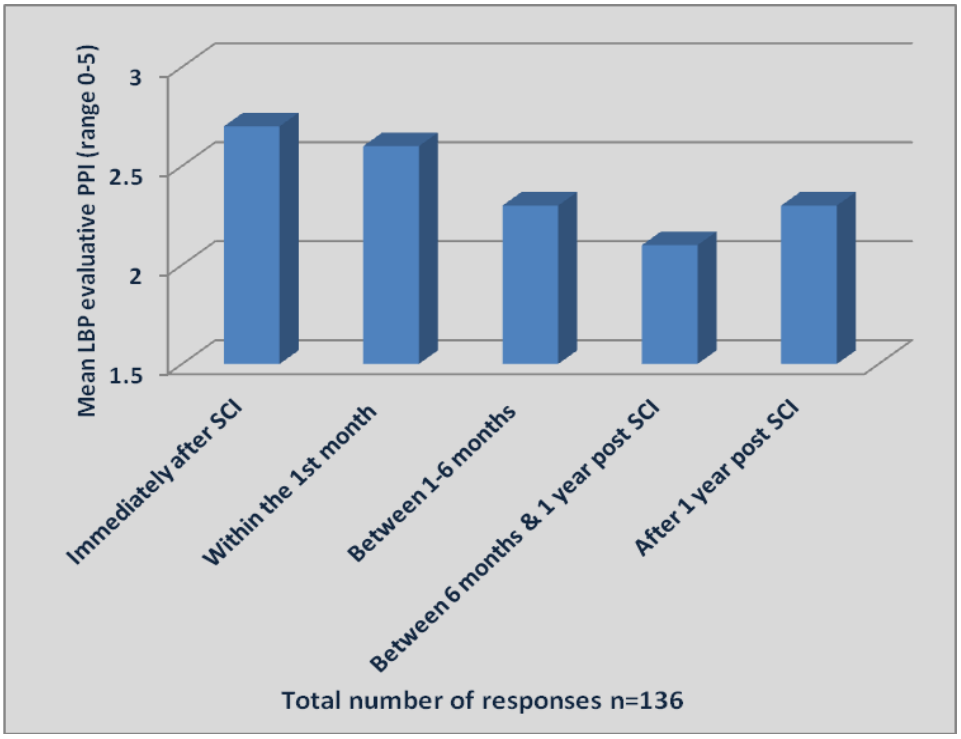

Figure 6.2.10 Mean evaluative overall LBP intensity in groups by LBP onset post iSCI.
Abbreviations: LBP, Low Back Pain; PPI, Present Pain Intensity; iSCI, incomplete Spinal Cord Injury.

6.2.10 LBP quality and intensity; relation to pain extent

The relation between pain extent and LBP quality or intensity was investigated using correlations. When the number of areas with pain increased people reported worse LBP quality in correlations that were of near moderate strength and of statistical significance; for the sensory dimension of PRI: $p \leq 0.001$, ($\rho=0.26$, Spearman's correlation, n=143); for the affective dimension of PRI: $p \leq 0.001$, ($\rho=0.28$, Spearman's correlation, n=146); and for total PRI: $p=0.002$, ($\rho=0.25$, Spearman's correlation, n=144) (Table 6.2.12).

The correlation was in the same direction and of similar strength between the number of areas with pain and the intensity of LBP but passed the Bonferroni α-level of significance for intensity of current pain: $p \leq 0.001$, ($\rho=0.22$, Spearman's correlation, n=119); and evaluative PPI for LBP: $p \leq 0.001$, ($\rho=0.27$, n=140, Spearman's correlation) (Table 6.2.12).

Table 6.2.12: Mean LBP quality and intensity in groups by the number of areas with pain. Correlations between groups

	S-PRI (range 0-33) mean±SD, min-max	**A-PRI (range 0-12)** mean±SD, min-max	**Total PRI (range 0-45)** mean±SD, min-max	**Intensity of current LBP (range 0-100)** mean±SD, min-max	**Intensity of LBP over last 1 month (range 0-100)** mean±SD, min-max	**Intensity of LBP over last 3 months (range 0-100)** mean±SD, min-max	**Evaluative overall intensity of LBP (range 0-5)**
1 area	6.3±0.6 6-7, n=3[1]	2.2±1.9 0-5, n=5	8.4±3.9 3-14, n=5	24.0±20.0 0-45, n=4	46.2±14.0 35-65, n=4	50.2±12.5 35-61, n=4	2.2±0.4 2-3, n=6
2 areas	8.6±7.1 0-29, n=34	2.0±2.6 0-10, n=32[2]	11.1±9.7 2-36, n=34	35.0±26.4 0-90, n=29	39.4±27.5 0-85, n=29	35.4±26.7 0-90, n=29	1.9±0.8 1-4, n=34
3 areas	7.2±4.5 1-16, n=29[1]	3.2±3.2 0-12, n=31	9.9±6.9 1-26, n=29[1]	44.3±29.2 0-92, n=19	44.3±29.3 0-95, n=19	46.5±27.8 0-97, n=19	2.3±1.4 1-5, n=31
4 areas	8.3±6.2 1-23, n=32[2]	2.6±3.0 0-10, n=33	11.6±9.2 1-39, n=33	43.0±29.2 0-100,n=26	44.7±26.6 0-80, n=26	49.8±25.4 0-85, n=25	2.3±0.9 1-4, n=31
5 areas	12.7±8.3 2-29, n=27	4.0±3.8 0-12, n=27	14.9±10.3 3-34, n=25	52.8±26.9 0-90, n=25	56.4±25.3 0-92, n=25	56.8±25.3 3-100,n=25	2.5±0.8 1-4, n=23
6 areas	12.9±8.2 0-24, n=9	6.3±3.5 0-11, n=9	19.1±10.7 3-34, n=9	43.4±35.3 0-97, n=8	48.6±35.0 0-98, n=8	48.1±34.5 0-95, n=8	2.9±1.5 0-4, n=7
7 areas	13.7±8.5 2-21, n=4	5.7±4.9 0-12, n=4	19.5±13.2 2-33, n=4	32.0±27.6 10-63, n=3	57.6±15.3 40-67, n=3	69.0±12.8 55-80, n=3	2.7±0.9 2-4, n=4
8 areas	13.5±13.4 4-23, n=2	3.0±2.8 1-5, n=2	16.5±16.3 5-28, n=2	54.5±27.6 35-74, n=2	65.5±28.9 45-86, n=2	64.5±27.6 45-84, n=2	3.0±1.4 2-4, n=2
9 areas	20.3±4.9 17-26, n=3	6.7±5.0 2-12, n=3	27.0±9.8 19-38, n=3	20.3±4.9 17-26, n=3	46.6±37.5 10-85, n=3	48.7±30.0 16-75, n=3	2.5±0.7 2-3, n=2
Statistical Test	ρ=0.26 **p≤0.001***** n=143	ρ=0.28, **p≤0.001***** n=146	ρ=0.25, **p=0.002**** n=144	ρ=0.22 **p≤0.001***** n=119	ρ=0.19 p=0.03[3] n=119	ρ=0.25 p=0.005[3] n=118	ρ=0.27 **p≤0.001***** n=140

[1]Two outliers, [2]One outlier, [3]not significant following application of the Bonferroni correction, **Significant at p≤0.01 level, ***Significant at p≤0.001 level, **in bold:** significant following application of the Bonferroni correction.

Abbreviations: PRI, Pain Rating Index; S-PRI, Sensory PRI; A-PRI, Affective PRI; PPI, Present Pain Intensity; LBP, Low Back Pain. *Statistical tests*: ρ, Spearman's rank correlation rho.

6.2.11 Conclusion

This chapter has confirmed that people with iSCI have pain which usually starts early following their injury, becomes chronic and tends to be continuous. It has also shown that people with iSCI have LBP of moderate intensity which increases when LBP becomes more regular. The onset of LBP is early after injury but LBP can also start after the first year following the injury. The demographic profile differences found to affect LBP presence and to pass the Bonferroni α-level of significance were the cause of injury and the level of injury. The level of injury significantly affected the quality of LBP as well.

This chapter has demonstrated the high presence of both pain in general, MSKP, but also of pain at the location of the lower back area following iSCI. It has also shown how the experience of pain, focusing on LBP, can be affected by demographic profile characteristics. The next chapter will describe the QoL of the respondents and will examine how the experience of pain, focusing on LBP, relates to QoL.

Chapter 7; Results: Quality of Life

Chapter Brief Table of Contents

"The quality of life is determined by its activities."

Aristotle (384 BC – 322 BC) – Greek Philosopher

(in Nicomachean Ethics[14])

7.1 Introduction

The previous chapter described the characteristics of the study participants and looked into the experience of pain. Extra emphasis was given to pain location, in particular at the lower back area.

Over the past few decades, as survival for people with a SCI has significantly increased, it has become important to identify ways to improve their QoL. Researchers increasingly include the study of QoL in their work. Currently there is a need to understand the barriers and challenges to a good QoL with the aim of being able to put in place appropriate treatment as well as prevention management. This chapter initially aims to describe the QoL of people with iSCI. Then it will investigate the answers to the question "what is the relationship, and what are the characteristics, between QoL and LBP in people with iSCI?"

The EQ-5D measurement was used to collect information about QoL. The results will be presented taking into account the user guide published by the EQ-5D,[341] which are divided into three areas; 1) a description of the health status profile based on its dimensions, 2) the EQ-5D index which is a *classification* of health state and 3) EQ-VAS which is the self-rated health *perception*[25].

7.2 Bonferroni correction

The main variables of interest involved in the analysis conducted for the present chapter were two; 1) the EQ-5D index, and 2) the EQ-VAS. Both were involved in 21 tests thus the α-level of significance for Bonferroni correction was set at p≤0.002 (Appendix 7: Table 7.1.1).

[25] For more details on EQ-5D refer back to Chapter 5, Section 5.9.2.

7.3 QoL characteristics, scoring and missing data

The EQ-5D is a self-completed QoL measure which consists of a descriptive system and a VAS. The descriptive system includes five dimensions, in which the respondent self-classifies him/herself on; 1) mobility, 2) self-care, 3) usual activities, 4) pain/discomfort and 5) anxiety/depression. Each dimension is scored on three levels ranked as none/no problem (1), some problems (2) to severe problems (3). The five dimensions of the EQ-5D descriptive system can give a total of 243 possible health states (or profiles), and each state is referred to using a 5-digit code. For example, the state 11111 indicates that there are no health problems in any dimension. The state 12123 indicates that there are no problems with mobility, some problems with self-care, none with usual activities, some problems with pain/discomfort and severe problems with anxiety/depression.

Responses to the five dimensions can be converted into a single summary index using set values. In this study the set values for the UK (UK-TTO) were used following the advice and guidelines of the EuroQuol group.[341] The best health state possible (11111) is given a mean value of 1.00, therefore the closer the mean value of the profile is to 1.00 the better the health state is. Finally, part of the EQ-5D is the EQ-VAS which is an overall self-rated health ranging from 0 to 100 and the higher the score the better the health status. Thus it measures the individual's *perception* of their health status.

There were some data missing in the dimensions in this study and responses ranged from 198 to 218. In general, there can be two forms of missing data in the EQ-5D: 1) item non-response which is when a person does not replied to at least one question of the EQ-5D, and 2) unique non-response when the whole EQ-5D questionnaire is not answered. Handling missing data in the EQ-5D when one of the dimensions is missing is not adequate and in most cases results in rejecting the whole questionnaire unless the measures are repeated.[250] The current survey had some item non-response related missing data and, since no repeated measures were made, all the EQ-5D was rejected when there were items missing. This left a total of 198 participants eligible to enter the analysis of QoL. The demographic profiles of the 21 people who were excluded were

compared with those of the 198 people included and no significant differences were found (Table 7.1).

7.4 QoL; general results

Overall, people described themselves as having some problems (level 2) for all dimensions. It was only for the "self-care" dimension that a few more people reported no problems (level 1) and more than one-fifth of people reported severe problems (level 3) for "pain/discomfort" (Figure 7.1). Following scoring of the dimensions, the mean index value was 0.4±0.3 (mean±SD) with a median of 0.51 (25 percentile at 0.06 and 75 percentile of 0.66). The EQ-5D index had a distribution that was bimodal indicating a non-normal distribution of the data (Appendix 7: Figure 7.2.1). This can be a problem when a parametric test, requiring a normal distribution, is used. In the current study, because the sample was large, the t-test[26] could be applied. However, the applicability of using a parametric test was checked throughout and, when not possible, a non-parametric test was used.

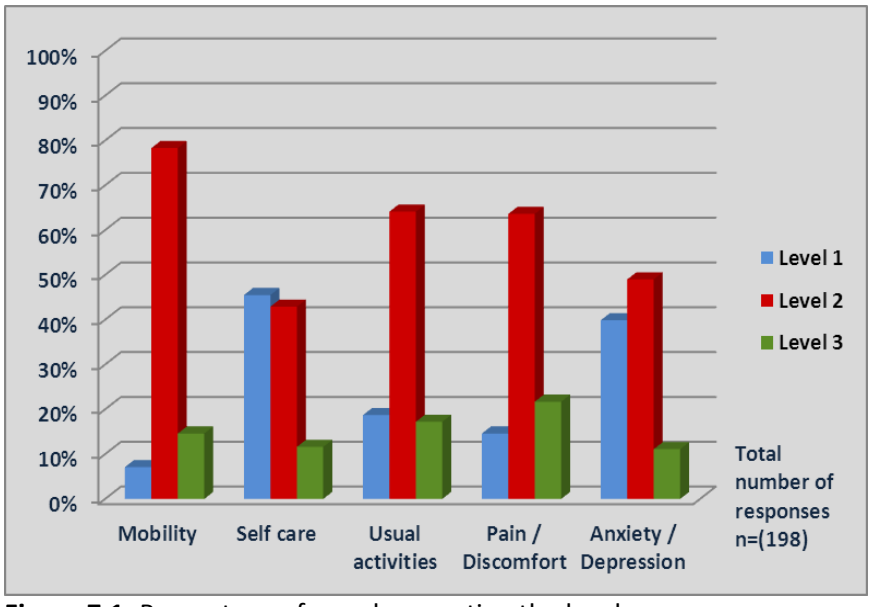

Figure 7.1: Percentage of people reporting the levels on each of the EQ-5D dimensions

[26] In highly skewed data to be able to apply t-test the groups need to be large (>50 in each group).[350]

Table 7.1: Differences in the demographic profile characteristics of people included and excluded in the analysis of the EQ-5D

Demographic characteristics	Excluded from analysis	Included in analysis	Statistical Test	Demographic characteristics	Excluded from analysis	Included in analysis	Statistical Test
Gender[1]			χ^2=0.55	**Age**	n=21	n=190	F=0.69
Male	n=14	n=120	p=0.45				p=0.40
Female	n=6	n=75					
Cause of injury			χ^2=0.32	**Age at injury**	n=21	n=189	F=0.35
Traumatic	n=16	n=139	p=0.56				p=0.55
Non-traumatic	n=5	n=59					
Type of injury[2]			χ^2=0.63	**Time since injury**	n=21	n=197	F=0.08
Tetraplegia	n=11	n=90	p=0.42				p=0.76
Paraplegia	n=9	n=107					
Country			χ^2=4.7	**Education**[3]			χ^2=0.55
USA	n=9	n=113	p=0.09	None/compulsory	n=2	n=22	p=0.45
UK	n=9	n=43	extended	High school	n=8	n=44	
Greece	n=3	n=42	χ^2	College/University	n=7	n=96	
				Master/PhD	n=3	n=34	
				Employment			χ^2=0.55
				Employed	n=14	n=105	p=0.45
				Unemployed	n=3	n=106	
				Retired	n=4	n=31	

[1]One person failed to report gender, [2]one persons failed to report type of injury, [3]one person failed to report education level.
Abbreviations: USA, United States of America; UK, United Kingdom; PhD, Doctor of Philosophy.
Statistical tests: F, One way ANOVA; χ^2, Pearson's or Extended Chi square.

Table 7.2, which ranks in decreasing order the mean index value, includes the first 20 health profiles. From the 243 possible health profiles, the total groups reported 64 health profiles. Table 7.2.1 in Appendix 7 presents all the health profiles. Table 7.2 below and 7.2.1 in Appendix 7 also present the mean perceived health status (EQ-VAS) and how much this mean ranges within each health profile. Overall it is noticed that as the EQ-5D index, thus the health state *classification*, is reduced then the EQ-VAS, thus the self-rated *perception* of the health, is also reduced. However, this is not constant as often it is seen that people who classify their health lower (mean index) perceive their health status higher (EQ-VAS) or vice versa. This is seen more clearly in the Appendix 7: Table 7.2.1 where all the health profiles are presented. Twenty people (10.1%) reported a profile with "some problems" for all five dimensions. Three (1.5%) reported severe problems (level 3) on all five dimensions and their perceived health state was very low (Appendix 7: Table 7.2.1).

The mean self-rated perceived health (EQ-VAS) was 62.95±22.5 (mean±SD) (median 68.5 and 25 percentile at 48.4 and 75 percentile of 80). The distribution of the data for the EQ-VAS in combination with the large group size was acceptable which allowed the use of parametric tests as required (Appendix 7: Figure 7.2).

Table 7.2: Frequency distribution of the first 20 reported health profiles with mean index and EQ-VAS values

Rank order	EQ-5D profile	Count	%	Index value (UK TTO)	Mean EQ-VAS	Range of mean EQ-VAS
1	11111	1	0.5	1.000	90.0	90
2	11211	2	1.0	0.883	72.5	70-75
3	21111	4	2.0	0.850	89.7	70-99
4	11112	1	0.5	0.848	60.0	60
5	21211	1	0.5	0.814	80.0	80
6	11121	2	1.0	0.796	88.5	80-95
7	11221	1	0.5	0.760	75.0	75
8	22111	3	1.5	0.746	96.0	95-98
9	21212	2	1.0	0.743	60.0	50-70
10	21121	8	**4.0**	0.727	85.4	80-95
11	11122	2	1.0	0.725	54.5	40-69
12	22211	3	1.5	0.710	73.3	65-85
13	21221	16	**8.1**	0.691	72.0	29-90
14	11222	3	1.5	0.689	69.3	58-90
15	21122	6	3.0	0.656	74.6	49.5-100
16	22212	5	2.5	0.639	59.0	50-85
17	21222	20	**10.0**	0.620	67.6	40-95
18	22221	10	**5.1**	0.587	58.0	20-90
19	22222	20	**10.1**	0.516	56.1	40-80
20	23211	2	1.0	0.331	90.0	90

The table is ranked in order of decreasing health according to the mean health index value; **in bold** are the 5 most frequently reported health profiles.
Abbreviations: EQ-5D, Quality of Life; EQ-VAS, Quality of Life Visual Analogue Scale.

7.5 QoL; relation to pain, MSKP and LBP

Analysis involving LBP presence in this chapter included referrals to "current" LBP. This was explained in Chapter 6 (Section 6.1.5).

In general, people with pain, LBP and MSKP replied similarly to the EQ-5D dimensions (Figure 7.4). People without MSKP or LBP still reported having some problems with "pain/discomfort" which indicated that they were referring to other types or locations of pain (Figure 7.5). More people without pain reported no or some problems with "self-care" (levels 1 and 2) and some problems with "usual activities" (level 2). Finally, people with pain, MSKP or LBP seemed to be more "anxious/depressed" than those without these pain categories (Figures 7.4, 7.5).

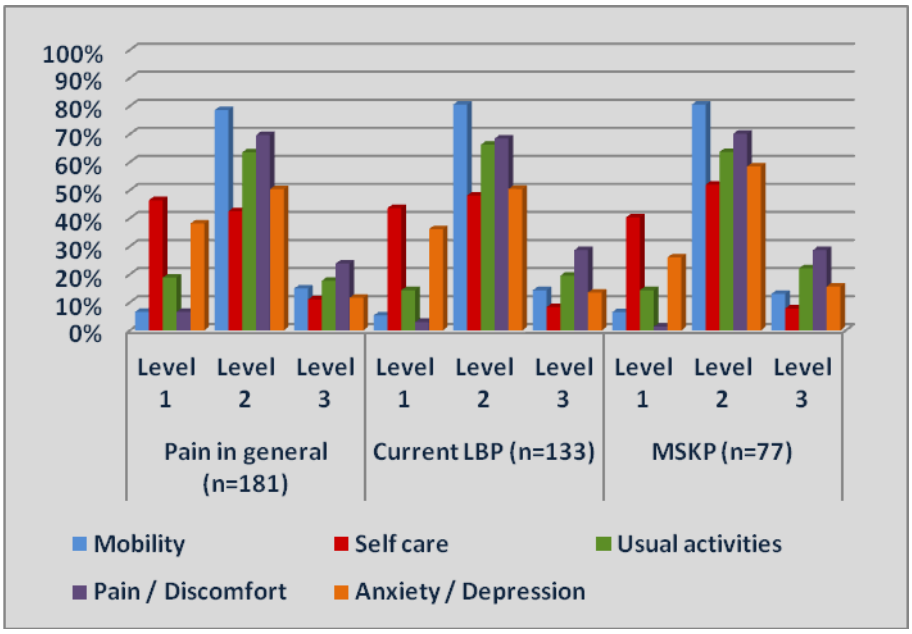

Figure 7.4: Percentage of people with pain, LBP and MSKP reporting each EQ-5D dimension
Abbreviations: LBP, Low Back Pain; MSKP, Musculoskeletal Pain.

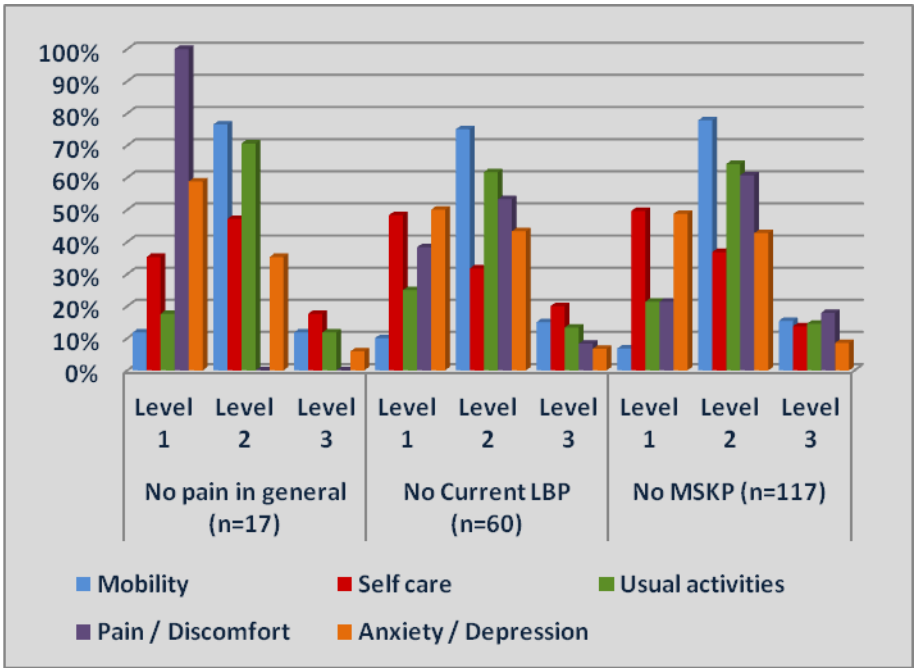

Figure 7.5: Percentage of people without pain, LBP or MSKP reporting each EQ-5D dimension
Abbreviations: LBP, Low Back Pain; MSKP, Musculoskeletal Pain.

Part of the first hypothesis theme was to investigate the differences in QoL between people with and without the pain categories of interest. The hypothesis (hypothesis 2) was threefold:

Hypothesis 0 (null): In people with iSCI there is no significant difference in QoL (EQ-5D index or EQ-VAS) between those with pain, MSKP or LBP and those without.

Hypothesis 2a: In people with iSCI there is a significant difference in QoL (EQ-5D index or EQ-VAS) between those with pain and those without.

Hypothesis 2b: In people with iSCI there is a significant difference in QoL (EQ-5D index or EQ-VAS) between those with MSKP and those without.

Hypothesis 2c: In people with iSCI there is a significant difference in QoL (EQ-5D index or EQ-VAS) between those with LBP and those without.

Scoring of the EQ-5D showed that people with pain, MSKP or LBP reported worse on the index but no difference passed the Bonferroni α-level of significance; for pain: $p \leq 0.01$, ($U=798$, Mann-Whitney U test, ES: $r=-0.23$, $n=198$); for current LBP: $p=0.004$, ($t=2.90$, 95% CI 03.05, 0.26, independent t-test, ES: $d=0.19$, $n=193$); for MSKP: $p=0.03$, ($t=2.13$, 95% CI 0.008, 0.2, independent t-test, ES: $d=0.008$, $n=194$) (Table 7.3, Figure 7.6).

People with pain (n=181) perceived their health as slightly worse than people without pain (n=17) but this difference was of small effect and not significant ($p=0.93$, 95% CI -5.95, 16.6, independent t-test, ES $d=0.24$). People with current LBP (n=133) perceived their self-rated health as significantly worse (58.0±22.3) than those without LBP with a much greater than typical effect size ($p \leq 0.001$, $t=4.48$, 95% CI 8.41, 21.6, ES $d=0.71$). Similarly, people with MSKP (n=77) perceived their self-rated health as significantly worse than people without MSKP (n=117) with a medium effect size (n=117) ($p \leq 0.01$, $t=2.55$, 95% CI 1.90, 14.82, ES $d=0.37$) (Table 7.4). These results indicate that when the type of pain is MSKP and when the location of pain is at the lower back then their impact on self-rated health perception is greater.

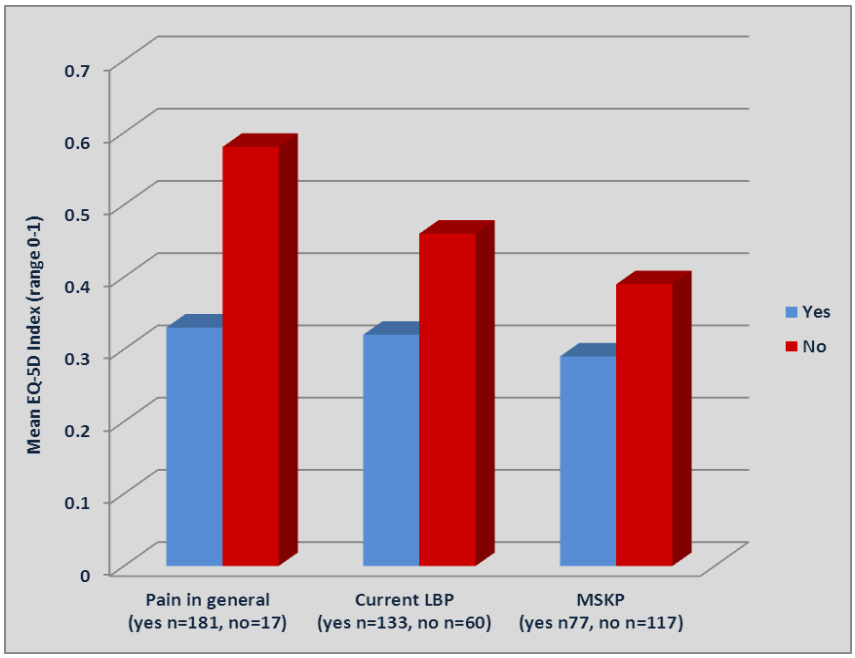

Figure 7.6: Mean EQ-5D index reported by people with and without pain, LBP or MSKP.
Abbreviations: EQ-5D index, Quality of Life index; LBP, Low Back Pain; MSKP, Musculoskeletal Pain.

Table 7.3: Characteristics of EQ-5D index in groups by pain presence ("Yes" and "No"). Differences in the EQ-5D between groups

		Yes	No	Statistical tests
Pain	n	181	17	U=798.0,
	Mean±SD	0.3±0.3	0.6±0.3	ES: r=-0.23
	Median	0.5	0.6	p≤0.01[1]
	Percentile 25th	0.008	0.3	
	Percentile 75th	0.65	0.8	
	Skewness	-0.5	-0.8	
	Kurtosis	-0.9	-0.7	
Current	n	133	60	t=2.90, df189,
LBP	Mean±SD	0.3±0.3	0.5±0.3	ES: d=0.19
	Median	0.5	0.6	p=0.004[1]
	Percentile 25th	-0.01	0.1	95% CI 0.05, 0.26
	Percentile 75th	0.6	0.7	
	Skewness	-0.4	-0.8	
	Kurtosis	-1.1	0.04	
MSKP	n	77	117	t=2.13, df192,
	Mean±SD	0.3±0.3	0.4±0.3	ES: d=0.008
	Percentile 25th	-0.05	0.1	p=0.03[1]
	Percentile 75th	0.6	0.7	95% CI 0.008, 0.2

[3]not significant post Bonferroni correction
Abbreviations: LBP, Low Back Pain; MSKP, Musculoskeletal Pain.
Statistical tests: U, Mann-Whitney U test; t, Independent t-test.

Table 7.4: Characteristics of EQ-VAS in groups by pain presence ("Yes" and "No"). Differences in the EQ-VAS between groups

		Yes	No	Statistical Tests
Pain	n	181	17	t=0.93, df196,
	Mean±SD	62.5±22.7	67.8±20.9	ES: d=24
	Percentile 25th	45	50	p=0.93
	Percentile 75th	80	85	95% CI -5.95, 16.60
LBP	n	133	60	t=4.48, df191,
	Mean±SD	58.0±22.3	73.0±19.8	ES: d=0.71
	Percentile 25th	60	60	**p≤0.001*** **
	Percentile 75th	90	90	95% CI 8.41, 21.6
MSKP	n	77	117	t=2.55, df192,
	Mean±SD	57.8±20.8	66.0±23.3	ES: d=0.37
	Percentile 25th	50	50	p≤0.01[1]
	Percentile 75th	85	85	95% CI 1.90, 14.82

[3]not significant post Bonferroni correction; ***Significant at p≤0.001 level, **in bold:** significant following application of the Bonferroni correction.
Abbreviations: LBP, Low Back Pain; MSKP, Musculoskeletal Pain.
Statistical tests: t, Independent t-test.

7.6 QoL; relation to demographic profile characteristics

Men (n=120) and women (n=76) responded similarly to the EQ-5D dimensions mainly reporting "some problems" with them. A small proportion (6%) of women, compared to men, reported having worse pain and discomfort. However, it appeared that women reported slightly more cases of "anxiety/depression" than men (Figure 7.7; Appendix 7: Table 7.3.1). Following scoring of the EQ-5D, the similarities between men (0.4±0.3, mean±SD) and women (0.3±0.3, mean±SD) were evident and there were no significant differences between the two sexes (p=0.13, t=1.48, 95% CI -0.02, 0.17, independent t-test) (Table 7.5; Appendix 7: Table 7.3.2). Despite males reporting slightly better self-rated health (64.0±23.9, mean±SD) compared to females (61.7±20.3, mean±SD) this was not a significant difference (p=0.5, t=0.67, 95% CI -4.33, 8.79, independent t-test) (Appendix 7: Table 7.3.2).

In Chapter 6 (Section 6.1.7) prior to application of the Bonferroni correction a higher proportion of females reported having MSKP. Taking into account the report by IASP[177] which advised to investigate pain-related variables by gender, the difference in mean EQ-5D index between those with and those without MSKP was tested with males and

females. However, this was not part of the main analysis and as such it is presented at Appendix 7, Table 7.3.3.

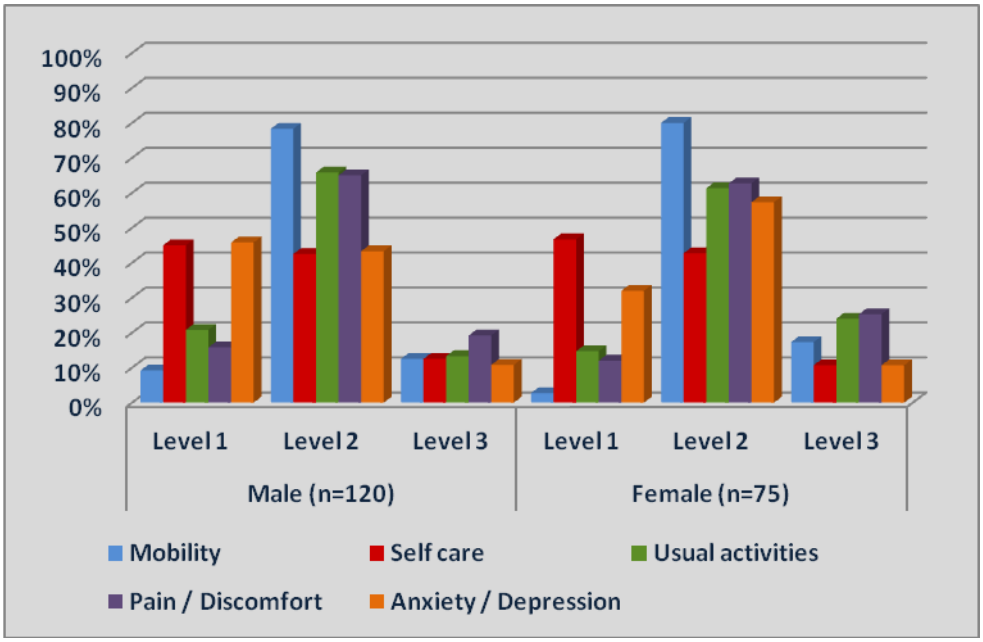

Figure 7.7: Percentage of men and women reporting each EQ-5D dimension

People with a traumatic cause of injury (n=139) reported fairly similar scores on the EQ-5D dimensions to people with a non-traumatic cause of injury (n=59). People from both groups reported having "some problems" on the dimensions. However, some individual differences emerged as people with a traumatic injury were less "anxious/depressed" and seemed to be more able to carry out their "usual activities" (Figure 7.8; Appendix 7: Table 7.3.1). After scoring the EQ-5D dimension, the similarities between people with traumatic (0.4±0.3, mean±SD) and non-traumatic injuries (0.3±0.4, mean±SD) were evident and no significant difference was found between them (p=0.07, U=3441.5, Mann-Whitney) (Table 7.5; Appendix 7: Table 7.3.4). People with a non-traumatic cause perceived their health to be lower (53.8±19.5, mean±SD) than those with a traumatic cause (66.8±22.7, mean±SD), but this difference failed to pass the Bonferroni α-level of significance (p=0.006, t=-2.85, 95% CI -43, -7.5, independent t-test, n=198) (Table 7.5; Appendix 7: Table 7.3.4).

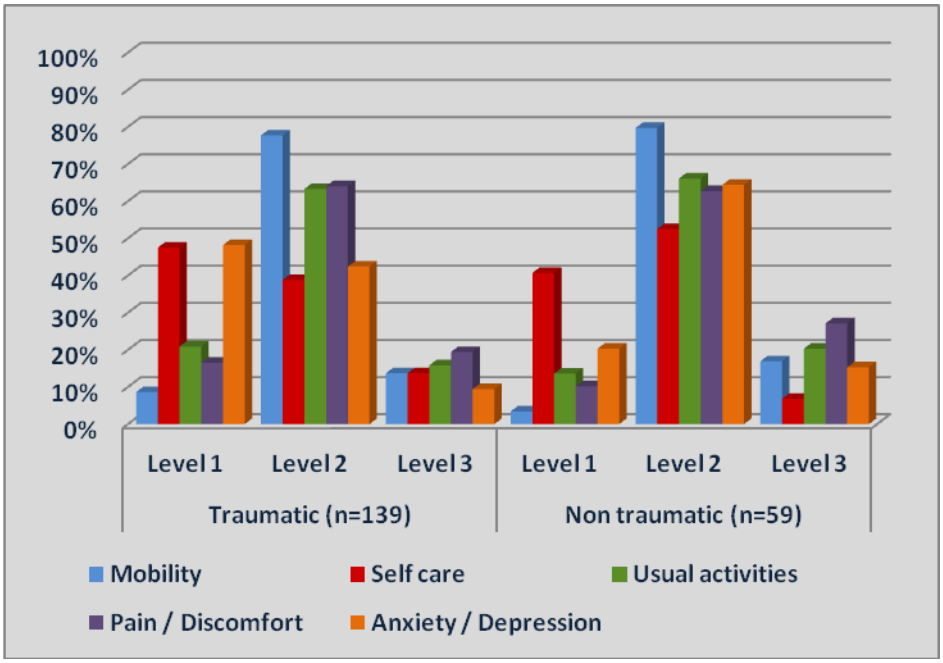

Figure 7.8: Percentage of people reporting each EQ-5D dimension divided into groups by cause of injury

The mean age of people was very similar across all five dimensions ranging from a low of 46.0±15.8 (mean±SD, "mobility" subscale for level 3) to a high of 51.1±13.7 (mean±SD, "self-care" subscale for level 2) (Appendix 7: Table 7.3.8). Following scoring of the dimensions, age did not correlate significantly with health state classification ($p=0.78$, $r=0.02$, Pearson's correlation, $n=190$). However, older people perceived their health as significantly worse ($p\leq0.001$, $r=-0.36$, Pearson's correlation) (Table 7.5).

Overall, people with tetraplegia (n=91) as well as people with paraplegia (n=107) reported some problems (level 2) on the EQ-5D dimensions. As expected, people with lower injuries reported better "self-care". Interestingly, people with higher injuries (tetraplegia) seemed to be less "anxious/depressed" (Figure 7.9; Appendix 7: Table 7.3.1). Scoring of EQ-5D dimensions confirmed that the differences between the two groups were not significant ($p=0.81$, $U=4772$, Mann-Whitney, $n=198$) (Table 7.5; Appendix 7: Table 7.3.5). Again of interest, people with tetraplegia perceived their self-rated health as better than those with paraplegia but this difference did not pass the Bonferroni α-level of significance ($p=0.017$, $t=2.41$, 95% CI 1.4, 13.93) (Table 7.7;

Appendix 7: Table 7.3.5). Analysis per the three levels of injury is presented at Appendix 7: Figure 7.3.1 and Tables 7.3.6-7.3.7.

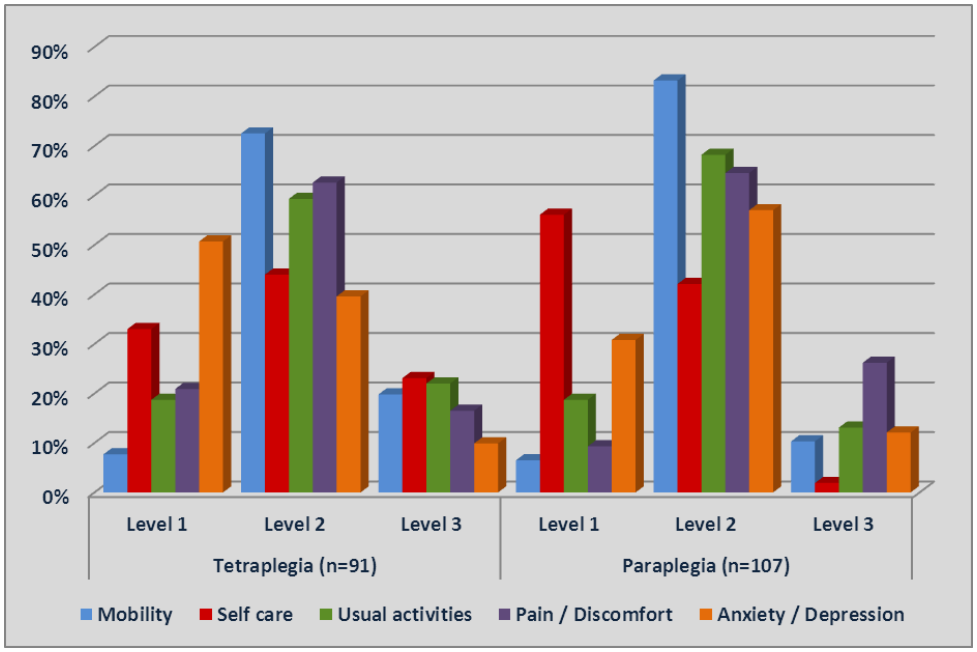

Figure 7.9: Percentage of people reporting each EQ-5D dimension divided into groups by level of injury
Abbreviations: EQ-5D, Quality of Life

People with a longer mean time since injury reported more severe problems on some dimensions (i.e. "mobility" and "pain/discomfort") while, on other occasions people with a longer time since injury reported less or even no problems (i.e. "usual activities" and "anxiety/depression") (Appendix 7: Table 7.3.11). Following scoring of the EQ-5D dimensions, it was found that time since injury did not correlate significantly with EQ-5D either on the index ($p=0.509$, $\rho=-0.04$, Pearson's correlation) or the perceived self-rated health of the respondents ($p=0.62$, $r=0.35$, Pearson's correlation). People perceived their self-rated health as better when the time since injury was longer in a correlation of moderate strength (Table 7.5).

Table 7.5: Summary results and statistical tests of EQ-5D and EQ-VAS reported by people divided into groups by demographic profile characteristics

		EQ-5D Index		EQ-VAS	
	n	**mean±SD**	**Statistical Tests**	**mean±SD**	**Statistical Tests**
Gender			t=1.48		t=0.67
Male	120	0.4±0.3	p=0.18	64.0±23.9	p=0.5
Female	76	0.3±0.3	95% CI -0.02, 0.17	61.7±20.3	95% CI -4.33, 8.79
Cause of Injury			U=3441.5		t=-2.85
Traumatic	139	0.4±0.3	p=0.07	66.8±22.7	p=0.006[3]
Non-traumatic	59	0.3±0.4		53.8±19.5	95% CI -43.0, -7.5
Age	190		r=-0.46		r=-0.36
			p=0.54		**p≤0.001*** **
Level of injury			U=4772		t(df196)=2.41
Tetraplegia	91	0.3±0.4	p=0.81	67.1±23.9	p=0.017[3]
Paraplegia	59	0.3±0.4		59.4±20.8	95% CI 1.4, 13.9
Time since injury	197		ρ=-0.04		r=0.35
			p=0.509		p=0.62
Marital status	194		t=0.02		t=-1017
Married/with partner		0.4±0.3	p=0.98	61.9±22.6	p=0.24
Single/divorced/widow		0.4±0.4	95% CI -0.10, 0.10	55.8±21.8	95% CI -10.5, 2.6
Education level	196		H=3.23		H=7.31
None or compulsory		0.4±0.4	p=0.35	52.1±22.5	p=0.06
High School		0.3±0.4		61.8±24.1	
Colleg/Bachel/Assoc		0.4±0.3		65.2±21.8	
Master's/PhD		0.4±0.3		65.3±21.2	
Employment status	197				
Employed[1]		0.5±0.3	H=14.06		
Unemployed[2]		0.2±0.4	**p≤0.001*** **		
Retired		0.4±0.3			

[1]including people in paid job, voluntary job, working from home and students, [2]including people unable to work, looking for a job and homemakers; [3]not significant post Bonferroni correction; ***Significant at p≤0.001 level, **in bold:** significant following application of the Bonferroni correction.

Abbreviations: EQ-5D index, Quality of Life index; EQ-VAS, Quality of Life Visual Analogue Scale; PhD, Doctor of Philosophy.

Statistical tests: U, Mann-Whitney U test; t, Independent t-test; r, Pearson's correlation; H, Kruskal-Wallis H test.

Three additional variables that were found in the literature to relate to QoL (marital status, education level and employment) were examined as well. Marital status was collated into two categories 1) people married or living with a partner or in a relationship and 2) people single or separated/divorced or widowed. The majority of

people from both categories said that they had some problems (level 2) for all health status dimensions. They reported no problems with "self-care" and a greater percentage of single people seemed to be less "anxious/depressed" than those with a partner. After scoring of the dimensions, the similarities between the two groups were confirmed, as no significant differences were found on the classification or perception of health status according to marital status (Table 7.5).

Education was grouped into four categories; 1) none or compulsory education, 2) high school, 3) college, associate degree or university bachelor degree and 4) master's or PhD. Overall, the groups did not differ much, however people with higher levels of education seemed to be less severely "anxious/depressed" and reported more cases of no problems with "self-care" (Appendix 7: Table 7.3.9). Following scoring of the five dimensions, it was found that people with different education levels did not differ significantly in their classification of health state or perception of self-rated health (Table 7.5).

Finally, in the case of employment status the categories were collated into three; 1) "employed" included people in a paid job, voluntary job, working from home and students, 2) "unemployed" included people unable to work, looking for a job and homemakers and 3) "retired". It was decided to put students under the "employed" category, even though in some cases they were not paid, because it was believed that studying involves tasks that many paid office-based jobs would also require. People reported very similarly on the five dimensions of health status, although those who were employed reported none or less severe problems with "self-care" and fewer cases of severe problems with "anxiety/depression". Scoring of the EQ-5D dimensions confirmed that there was a significant difference in the EQ-5D index by education level ($p=0.001$, $H=14.06$, Kruskal-Wallis H test, $n=197$). Two-group analysis showed that this difference was between employed and unemployed people, with employed people reporting a better mean index ($p\leq0.001$, $U=2111$, Mann-Whitney U test, $n=166$, Table 7.7).

Table 7.7: Two-group comparisons for EQ-5D between groups divided by employment status

n, mean±SD, min-max	**Unemployed** n=61, 0.2±0.4, -0.6, 0.8	**Retired** n=31, 0.3±0.3, -0.2, 0.7
Employed, n=105 0.4±0.5, -0.3, 1	U=2111 **p≤0.001*** **	U=1313.5 p=0.10
Unemployed		U=77.5 p=0.16

***Significant at p≤0.001 level; **in bold:** significant following application of post hoc Bonferroni correction.
Statistical Test: U, Mann-Whitney U test.

Similarly, people in employment perceived their health status as significantly better (p≤0.001, F=8.55, one-way ANOVA, n=197). Two-group comparisons using Bonferroni post hoc analysis showed that this difference was between employed and unemployed people as well as between retired and employed (Table 7.8).

Table 7.8: Two-group comparisons for EQ-VAS between groups divided by employment status

n, mean±SD, min-max	**Unemployed** n=61, 59.2±25.2, 0-100	**Retired** n=31, 51.9±21.7, 10-98
Employed, n=105 68.7±19.3, 5-100	I-J=9.4, 95% CI 1.02, 17.8, **p=0.02****	I-J=16.7, 95% CI 6.02, 27.4, **p≤0.01****
Unemployed		I-J=2.8, 95% CI -4.01, -18.5, p=0.28

**Significant at p≤0.01 level;
in bold: significant following application of post hoc Bonferroni correction.

7.7 QoL; relation to pain/LBP days, free periods, onset

As the number of pain or LBP days felt per month increased people with pain or LBP reported higher percentages of some or severe problems with “mobility”. Between people divided into groups of varying pain/LBP days there were some differences in their reported problems, for example, more people who felt LBP daily reported moderate to extreme “anxiety/depression”, however these differences were not very high. It seemed that as the pain or LBP days felt per month increased so did “anxiety/depression” (Appendix 7, Table 7.5.1).

After scoring the EQ-5D dimensions, it was found that as the number of pain days felt in a month increased, the health status classification was significantly worse ($p \leq 0.001$, $\rho = -0.24$, Spearman's correlations, n=176). The same was found when the LBP days felt per month increased ($p \leq 0.001$, $\rho = -0.30$, Spearman's correlations, n=148) (Appendix 7: Table 7.4.1). When the number of pain/LBP days felt per month increased, the perceived self-rated health decreased; for pain days: $p = 0.03$, ($\rho = -0.16$, Spearman's) and for LBP days: $p = 0.003$, ($\rho = -0.35$, Spearman's) and though not passing the Bonferroni α-level of significance, it was close, particularly in the case of the increase of LBP days (Appendix 7: Table 7.4.1).

When the regularity of pain- or LBP-free weeks decreased, more people reported severe problems with all five EQ-5D dimensions (Appendix 7: Table 7.4.2). People with no LBP breaks reported severe problems slightly more often on the dimensions of QoL than those who reported having no breaks in their pain in general (Appendix 7: Table 7.4.2). That may imply that when pain is general, maybe not located at the lower back, the problems with QoL are not as severe. Though the current data cannot confirm this (as in the "pain in general" group those with LBP are also included), it may be a possibility.

After scoring the EQ-5D, it became apparent that as the frequency of pain-free weeks decreased so did the health status classification. The relationship between the EQ-5D index and the frequency of pain- or LBP-free weeks was significant; for pain free weeks: $p \leq 0.001$, ($\rho = -0.30$, Spearman's correlation, n=166); for LBP-free weeks: $p \leq 0.001$, ($\rho = -0.31$, Spearman's, n=112) (Appendix 7: Table 7.4.3). However, the regularity of the pain- or LBP-free weeks did not correlate significantly with how people perceived their self-rated health despite the direction of the correlation being similar to how people classified their health state (Appendix 7: Table 7.4.4).

The relationship between QoL and the onset of pain/LBP was part of the second hypotheses theme (hypothesis 6). The following was hypothesised:

Hypothesis 0 (null): In people with iSCI there is no significant correlation between QoL (EQ-5D index or EQ-VAS) and the onset of pain or LBP post iSCI.

Hypothesis 6a: In people with iSCI there is a significant correlation between QoL (EQ-5D index or EQ-VAS) and the onset of pain post iSCI.

Hypothesis 6b: In people with iSCI there is a significant correlation between QoL (EQ-5D index or EQ-VAS) and the onset of LBP post iSCI.

Slightly more people who had LBP onset immediately after their injury reported more problems with anxiety/depression in comparison with people with immediate pain onset following injury (Table 7.13). Following scoring of the EQ-5D dimensions it was seen that the correlation between EQ-5D index and pain onset was very weak and not significant (p=0.65, ρ=0.035, Spearman's, 95%CI -0.10, 0.16, n=171) (Table 7.9). But the correlation between the EQ-5D index and LBP onset was slightly stronger although it did not pass the Bonferroni α-level of significance (p=0.02, ρ=0.19, Spearman's correlation, 95%CI 0.04, 0.33, n=130) (Table 7.10).

Overall, it was seen that the later the onset of pain or LBP, post iSCI, the better people perceived their self-rated health but these correlations failed to pass the Bonferroni α-level of significance; for pain onset: p=0.017, (ρ=0.18, Spearman's correlation, 95%CI 0.05, 0.30, n=171) (Table 7.11, Figure 7.10); for LBP onset: p=0.01, (ρ=0.21, Spearman's correlation, 95%CI 0.06, 0.35, n=130) (Table 7.12, Figure 7.10).

Table 7.9: EQ-5D index in groups divided by time of pain onset post iSCI. Correlations between EQ-5D index and pain onset

Pain onset	Immediately after iSCI	Within the 1st month post iSCI	Between 1-6 months post iSCI	Between 6 months & 1 year post iSCI	After 1 year post iSCI	Statistical tests
n	75	32	34	10	20	p=0.65
Mean±SD	0.3±0.3	0.4±0.3	0.3±0.3	0.2±0.4	0.4±0.4	ρ=0.035
Median	0.5	0.5	0.5	0.2	0.6	95%CI
Percentile 25th	-0.01	0.1	-0.05	-0.05	0.01	-0.10, 0.16,
Percentile 75th	0.6	0.6	0.6	0.6	0.7	n=171
Skewness	-0.3	-0.5	-0.6	-0.6	-0.9	
Kyrtosis	-1.1	-1.4	-1.2	-0.2	-0.4	

Abbreviations: EQ-5D index, Quality of Life index; iSCI, incomplete Spinal Cord Injury, *Statistical tests*: ρ, Spearman's pho correlation, CI: Confidence Interval.

Table 7.10: EQ-5D index in groups divided by time of LBP onset post iSCI. Correlation between EQ-5D index and LBP onset

LBP onset	Immediately after iSCI	Within the 1st month post iSCI	Between 1-6 months post iSCI	Between 6 months & 1 year post iSCI	After 1 year post iSCI	Statistical tests
n	45	19	26		27[1]	p=0.02[2]
Mean±SD	0.3±0.4	0.3±0.3	0.3±0.3	0.3±0.4	0.5±0.3	ρ=0.19
Median	0.2	0.5	0.5	0.6	0.6	95%CI 0.04,
Percentile 25th	-0.03	-0.008	-0.04	-0.1	0.3	0.33, n=130
Percentile 75th	0.6	0.6	0.7	0.6	0.7	
Skewness	0.03	-0.6	-0.4	-0.6	-1.3	
Kyrtosis	-0.9	-1.2	-1.4	-1.6	0.3	

[1]One outlier eliminated from analysis, [2]not significant post Bonferroni correction
Abbreviations: EQ-5D index, Quality of Life index; EQ-VAS, Quality of Life Visual Analogue Scale; LBP, Low Back Pain; iSCI, incomplete Spinal Cord Injury;
Statistical tests: ρ, Spearman's pho correlation; CI, Confidence Interval

Table 7.11: EQ-VAS in groups divided by time of pain onset post iSCI. Correlation between EQ-VAS and pain onset

	Immediately after iSCI	Within the 1st month post iSCI	Between 1-6 months post iSCI	Between 6 months & 1 year post iSCI	After 1 year post iSCI	Statistical tests
n	75	32	34	10	20	p=0.017[1]
Mean±SD	57.3±23.5	64.4±19.7	66.8±19.4	51.4±30.7	72.2±23.9	ρ=0.18
Median	55	66	68.5	54.7	75.5	95%CI
Percentile 25th	40	46.2	50	28.7	53.7	0.05,
Percentile 75th	77	82	81.2	80	95	0.30,
Skewness	-0.2	-0.3	-0.5	-0.5	-0.8	n=171
Kyrtosis	-0.8	-1.3	-0.6	-0.8	-0.4	

[1]not significant post Bonferroni correction;
Abbreviations: EQ-VAS, Quality of Life Visual Analogue Scale; iSCI, incomplete Spinal Cord Injury; *Statistical tests*: ρ, Spearman's pho correlation; CI, Confidence Interval

Table 7.12: Descriptive of EQ-VAS for LBP onset following iSCI

	Immediately after iSCI	Within the 1st month post iSCI	Between 1-6 months post iSCI	Between 6 months & 1 year post iSCI	After 1 year post iSCI	Statistical tests
n	45	19	26	13	27[1]	p=0.01[2]
Mean±SD	53.4±24.6	55.1±18.1	60.6±21.1	63.6±18.1	68.8±22.2	ρ=0.21
Median	55	55	65	60	71	95%CI 0.06,
Percentile 25th	34.5	40	43.7	49.7	60	0.35, n=130
Percentile 75th	76	75	76.2	82.5	85	
Skewness	-0.3	-0.05	0.1	0.2	-0.7	
Kyrtosis	-1.0	-1.5	-0.8	-1.4	-0.2	

[1]One outlier eliminated from analysis; [2]not significant post Bonferroni correction
Abbreviations: EQ-VAS, Quality of Life Visual Analogue Scale; iSCI, incomplete Spinal Cord Injury; *Statistical tests:* ρ, Spearman's pho correlation; CI, Confidence Interval

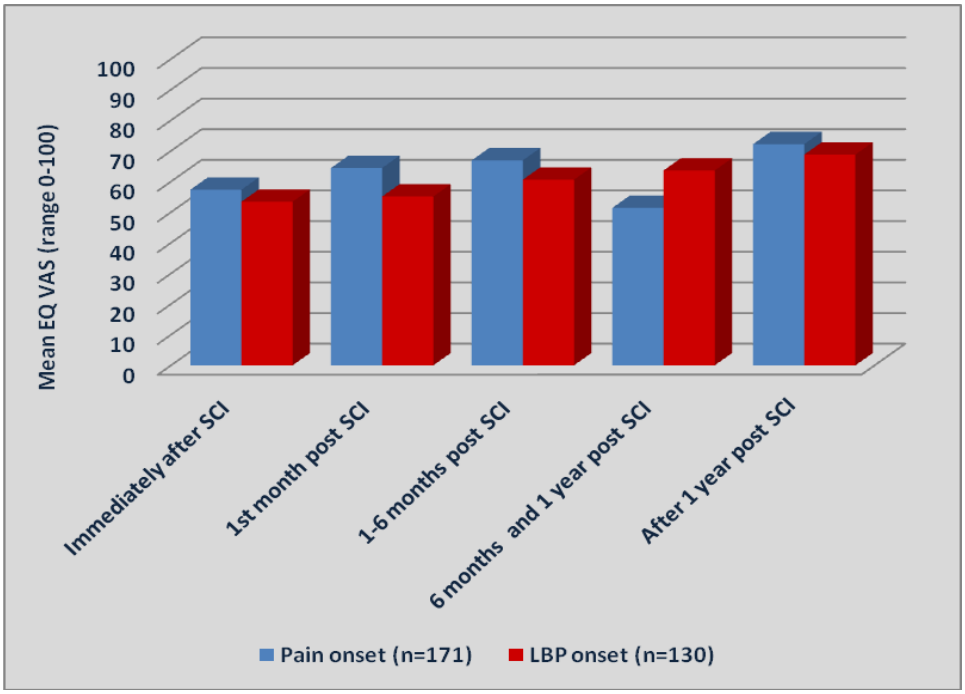

Figure 7.10: Mean EQ-VAS reported by groups of people divided per pain/LBP onset post iSCI.
Abbreviations: EQ-VAS, Quality of Life Visual Analogue Scale; iSCI, incomplete Spinal Cord Injury; LBP, Low Back Pain.

7.8 QoL; relation to pain extent

Data analysis showed that as the number of areas with pain on the body increased, the mean EQ-5D index significantly decreased thus people classified their health state lower. Though of nearly moderate strength it did not pass the Bonferroni α-level of

significance (p=0.01, r=-0.25, n=174, Pearson's correlation). The same was found between the perception of self-rated health and the number of areas with pain (p=0.05, r=-0.21, n=174, Pearson's correlation).

In Chapter 6, females were found to report significantly more areas with pain on the body (Section 6.2.5) thus, the relationship between QoL and number of areas with pain was investigated by gender. When the number of areas with pain increased in males, the EQ-5D index decreased with a correlation of moderate strength (p=0.02, r=-0.21, Pearson's correlation, n=107). The same was found with females (p=0.04, r=-0.25, Pearson's correlation, n=65). Finally, with males, the increased number of areas with pain correlated with a decreased perception of self-rated health (EQ-VAS) (p≤0.01, r=-0.10, Pearson's correlation, n=107) but this correlation was very weak among females (p=0.42, r=-0.10, Pearson's correlation, n=65). None of the above correlations were significant following application of the Bonferroni correction.

7.9 QoL; relation to LBP quality and intensity

The third hypothesis theme examined the relationship of LBP quality and intensity with a number of variables including QoL. Earlier analysis found no gender differences in quality and intensity of LBP or any other EQ-5D reports. Therefore, there was no need to examine the relationship between QoL and LBP quality or intensity by gender.

Data showed that as quality of LBP (PRI) became worse (increased), more people reported severe levels on the EQ-5D dimensions. This was more obvious for the dimensions of "usual activities", "pain/discomfort" and "anxiety/depression" (Table 7.15 and Figure 7.11).

Table 7.13: Percentage of people reporting the EQ-5D dimensions divided in groups by time of pain and LBP onset post iSCI

		Pain onset after iSCI % n=171 [1]					LBP onset after iSCI % n=131 [1]				
		Immediately after iSCI	Within 1st month	1-6 months	6 months – 1 year	After 1 year	Immediately after iSCI	Within 1st month	1-6 months	6 months – 1 year	After 1 year
Mobility	Level 1	6.7	6.3	5.9	0	5	6.7	15.8	3.8	0	3.6
	Level 2	82.7	78.1	85.3	70	65	82.2	73.7	80.8	92.3	82.1
	Level 3	10.7	15.6	8.8	30	30	11.1	10.5	15.4	7.7	14.3
Self-Care	Level 1	45.3	50.0	44.1	30	50	44.4	42.1	42.3	46.2	57.1
	Level 2	48	34.4	41.2	60	30	51.1	47.4	53.8	38.5	32.1
	Level 3	6.7	15.6	14.7	10	20	4.4	10.5	3.8	15.4	10.7
Usual Activities	Level 1	13.3	21.9	11.8	20	30	15.6	15.8	11.5	15.4	21.4
	Level 2	65.3	68.8	70.6	50	55	60.0	68.4	69.2	69.2	71.4
	Level 3	21.3	9.4	17.6	30	15	24.4	15.8	19.2	15.4	7.1
Pain / Discomfort	Level 1	6.7	0	2.9	0	15	2.2	5.3	11.5	0	7.1
	Level 2	64.0	81.3	70.6	70	75	57.8	68.4	65.4	69.2	78.6
	Level 3	29.3	18.8	26.5	30	10	40.0	26.3	23.1	30.8	14.3
Anxiety / Depression	Level 1	40.0	28.1	38.2	20	50	33.3	21.1	30.8	38.5	46.4
	Level 2	44.0	68.8	50.0	60	40	51.1	63.2	57.7	53.8	46.4
	Level 3	16.0	3.1	11.8	20	10	15.6	15.8	11.5	7.7	7.1

[1] Including only people with pain/LBP and excluding those who did not recall when the onset of their pain/LBP was.

Abbreviations: EQ-5D, Quality of Life; LBP, Low Back Pain; iSCI, incomplete Spinal Cord Injury

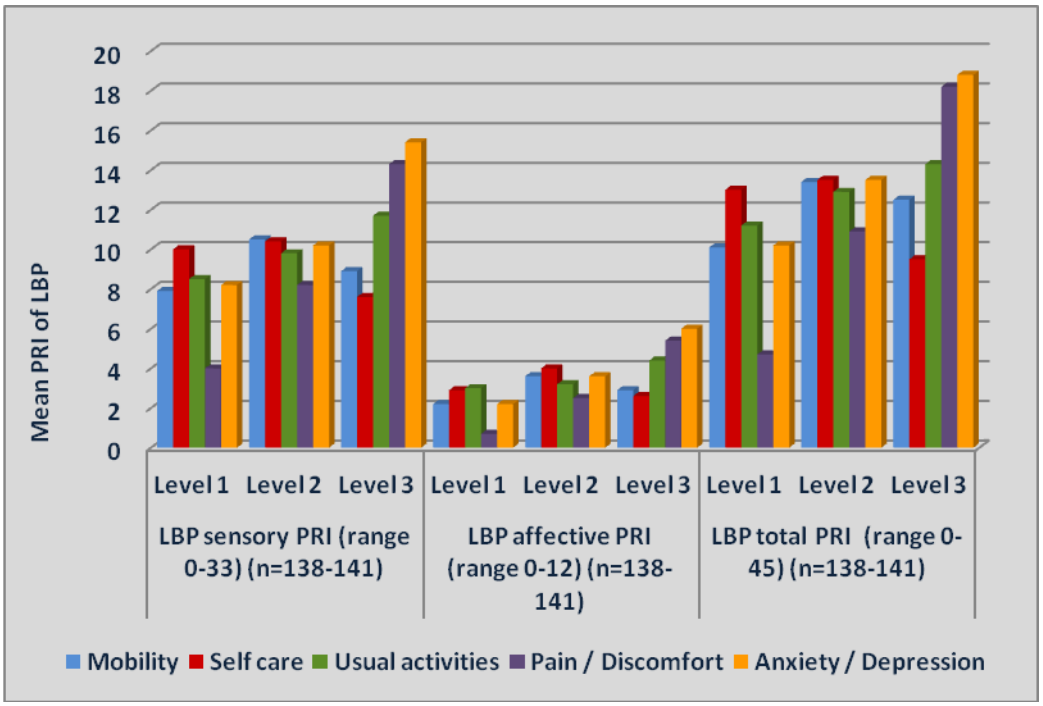

Figure 7.11: Mean LBP quality and intensity in groups by EQ-5D dimensions
Abbreviations: PRI, Present Rating Index; LBP, Low Back Pain

A correlation between QoL and quality of LBP had been hypothesised as follows:

Hypothesis 0 (null): In people with iSCI there is no significant correlation between QoL (EQ-5D index or EQ-VAS) and quality (sensory, affective or total PRI) of LBP.

Hypothesis 10a: In people with iSCI there is a significant correlation between QoL (EQ-5D index or EQ-VAS) and the sensory dimension of LBP.

Hypothesis 10b: In people with iSCI there is a significant correlation between QoL (EQ-5D index or EQ-VAS) and the affective dimension of LBP.

Hypothesis 10c: In people with iSCI there is a significant correlation between QoL (EQ-5D index or EQ-VAS) and the total PRI of LBP.

Analysis verified that as sensory dimension became worse (increased), the health state classification significantly decreased ($p \leq 0.001$, $r=-0.29$, Pearson's correlation, 95%CI -0.42, -0.14, n=141). The same significant correlation was verified for the affective

dimension (p≤0.001, r=-0.32, Pearson's correlation, 95%CI -0.45, -0.18, n=141) and for total PRI (p≤0.001, r=-0.26, Pearson's correlation, 95%CI -0.39, -0.11).

People perceived their self-rated health to be worse when the quality of LBP became worse but these correlations were not statistically significant and overall they were less strong; for the affective dimension: p≤0.01, (r=-0.27, Pearson's correlation, 95%CI -0.40, -0.11, n=141); for the sensory dimension: p=0.21, (r=-0.19, Pearson's correlation, 95%CI -0.33, -0.04, n=141) and for the total PRI: p=0.24, (r=-0.10, Pearson's correlation, 95%CI -0.25, 0.05). Thus the above null hypothesis cannot be rejected when reference is made to the classification of health state and quality of LBP.

In Chapter 6, it was seen that the intensity of LBP is important in the experience of pain for people with iSCI. Here it can be seen that when the mean intensity of the current LBP increases, more people report severe problems with the health status dimensions (Figure 7.12). In particular people with severe "pain/discomfort" and "anxiety/depression" (level 3) also reported the highest mean intensity of current LBP (61.3±28.1 and 59.4±23.9, mean±SD, respectively) (Tables 7.15, 7.16). This is a clear suggestion that experiencing a higher intensity of pain at this location affects QoL.

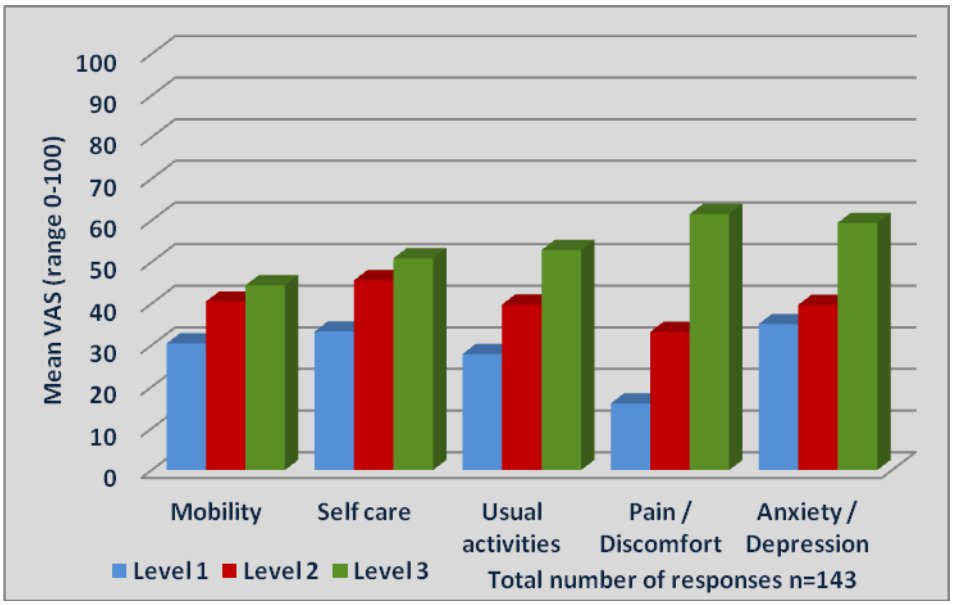

Figure 7.12: Mean intensity of current LBP reported by people divided into groups by EQ-5D dimensions
Abbreviations: VAS, Visual Analogue Scale.

A correlation between QoL and LBP intensity was hypothesised (hypothesis 11) as follows:

Hypothesis 0 (null): In people with iSCI there is no significant correlation between QoL (EQ-5D index or EQ-VAS) and intensity of LBP.

Hypothesis 11a: In people with iSCI there is a significant correlation between QoL (EQ-5D index or EQ-VAS) and current intensity of LBP.

Hypothesis 11b: In people with iSCI there is a significant correlation between QoL (EQ-5D index or EQ-VAS) and intensity of LBP over the last 1 month.

Hypothesis 11c: In people with iSCI there is a significant correlation between QoL (EQ-5D index or EQ-VAS) and intensity of LBP over the last 3 months.

Hypothesis 11d: In people with iSCI there is a significant correlation between QoL (EQ-5D index or EQ-VAS) and evaluative overall intensity of LBP (PPI).

Following scoring of the EQ-5D index and applying correlations it was confirmed that worse intensity significantly correlated with worse health state *classification*. All correlations were of high strength (Table 7.14). The same was found about the *perception* of self-rated health which significantly dropped when intensity of LBP (all time periods) increased. 95% CI were also not wide; as a result, the null hypothesis can be rejected (Table 7.14).

Table 7.14: Correlations between intensity of LBP and quality of life

	Intensity of Current LBP n=115	**Intensity of LBP over last 1 month** n=113	**Intensity of LBP over last 3 months** n=112	**Evaluative LBP intensity** n=130
EQ-5D index	r=-0.47 **p≤0.001*** ** 95%CI, -0.59, -0.33	r=-0.39 **p≤0.001*** ** 95%CI, -0.52, -0.24	r=-0.31 **p≤0.001*** ** 95%CI, -0.46, -0.15	r=-0.39 **p≤0.001*** ** 95%CI, -0.51, -0.26
EQ-VAS	r=-0.43 **p≤0.001*** ** 95%CI, -0.79, -0.28	r=-0.45 **p≤0.001*** ** 95%CI, -0.57, -0.30	r=-0.39 **p≤0.001*** ** 95%CI, -0.62, -0.24	r=-0.38 **p≤0.001*** ** 95%CI, -0.50, -0.25

***Significant at p≤0.001 level, **in bold:** significant following application of the Bonferroni correction.
Abbreviations: EQ-5D index, Quality of Life index; EQ-VAS, Quality of Life Visual Analogue Scale; LBP, Low Back Pain.
Statistical Tests: r, Pearson's correlation; CI, Confidence Interval

7.10 Conclusion

This chapter analysed the data collected about QoL and showed that people with iSCI report reduced QoL. All the dimensions that were measured as part of health status were affected. The findings confirm that the presence of pain in iSCI negatively affects QoL. A new finding is that LBP presence also negatively affects health status in people with iSCI. The more persistent pain or LBP are, the worse the health status. When the quality of LBP gets worse people *classify* their health status as worse but they do not *perceive* their health status as worse. However, when the intensity of LBP gets worse, then people perceive their health status as worse too. This confirms the importance of the intensity of this type of pain experience on QoL.

The next chapter will describe the functional independence of the respondents and will examine the impact of pain, MSKP and, in particular, LBP on it.

Table 7.15: Mean LBP quality and intensity in groups divided by EQ-5D dimensions

		S-PRI n, mean±SD, min-max, median	A-PRI n, mean±SD, min-max, median	Total S & A n, mean±SD, min-max, median	LBP intensity (0-100) n, mean±SD, min-max, median
Mobility mean±SD min-max, median, n	Level 1	n=7, 7.9±3.7 3-12, 10	n=7, 2.2±2.2 0-6, 2	n=7, 10.1±5.7 3-18, 13	n=8, 41.4±28.5 0-70, 22.7
	Level 2	n=117, 10.5±8.1 0-33, 8	n=117, 3.6±3.7 0-12, 2	n=114, 13.4±10.5 1-41, 10	n=115, 42.9±28.7 0-100, 35
	Level 3	n=21[1], 9.6±6.9 2-2, 6	n=22, 2.9±3.3 0-12, 2	n=22, 12.5±9.5 2-38, 8.5	n=20, 44.4±25.7 0-80, 50
Self-Care mean±SD min-max, median	Level 1	n=68, 10.0±7.6 1-29, 7.5	n=68, 2.9±3.1 0-12, 2	n=68, 13.0±10.4 1-41, 9.5	n=65, 36.7±29.3 0-100, 24.5
	Level 2	n=68[1], 10.4±8.0 0-33, 8	n=68, 4.0±3.8 0-12, 3	n=66, 13.5±10.0 1-39, 12	n=66, 47.3±26.3 0-90, 49.5
	Level 3	n=14[1], 7.6±5.5 2-26, 6	n=15[1], 2.6±3.8 0-12, 0	n=14[1], 9.5±7.7 2-29, 8	n=12, 53.0±29.1 0-97, 59
Usual Activities N, mean±SD min-max, median	Level 1	n=24[1], 8.5±5.6 2-30, 7	n=25[1], 3.0±2.90 0-11, 3	n=24, 11.2±7.5 1-25, 10	n=22, 32.9±25.3 0-70, 21.2
	Level 2	n=98[1], 9.8±7.5 0-33, 7	n=99, 3.2±3.4 0-12, 2	n=98, 12.9±10.2 1-39, 10	n=94, 42.3±28.7 0-100, 35
	Level 3	n=28, 11.7±8.6 0-29, 8.5	n=28, 4.4±4.4 0-12, 3	n=26, 14.3±10.7 2-38, 13.5	n=27, 52.7±26.7 0-90, 58
Pain / Discomfort N, mean±SD min-max, median	Level 1	n=3, 4.0±1.7 0-5, 5	n=3, 0.7±1.1 0-2, 0	n=3, 4.7±2.5 2-7, 5	n=5, 16.0±24.8 0-60, 5
	Level 2	n=103[2], 8.2±5.9 0-29, 6	n=105[2], 2.5±2.9 0-11, 2	n=104[1], 10.9±8.5 1-36, 8	n=98, 35.0±22.8 0-80, 29.5
	Level 3	n=43, 14.3±9.0 0-33, 13	n=43, 5.4±4.1 0-12, 6	n=40, 18.2±11.2 2-41, 18	n=40, 64.2±27.7 0-100, 70
Anxiety / Depression N, mean±SD min-max, median	Level 1	n=56[1], 8.2±6.3 1-30, 5.5	n=57, 2.2±2.6 0-11, 2	n=56[1], 10.2±8.1 1-29, 7.5	n=53, 35.4±28.6 0-97, 29
	Level 2	n=75, 10.2±7.9 0-29, 8	n=75, 3.6±3.6 0-12, 3	n=74, 13.5±10.6 1-39, 10	n=72, 44.4±26.2 0-100, 36.5
	Level 3	n=19, 15.4±8.0 4-33, 15	n=19, 6.0±4.4 0-12, 6	n=17, 18.8±9.9 3-38, 17	n=18, 63.7±23.8 20-90, 66.5

[1]One outlier eliminated, [2]Two outliers eliminated.

Abbreviations: PRI, Present Rating Index; S-PRI, Sensory PRI; A-PRI, Affective PRI; NRS, Numeric Rating Scale; LBP, Low Back Pain.

Table 7.16: Mean evaluative overall intensity of LBP (PPI) in groups divided by EQ-5D dimensions

		Evaluative PPI for LBP						
		Total mean±SD, min-max, median	**No pain** % n=2	**Mild** % n=25	**Discomforting** % n=56	**Distressing** % n=36	**Horrible** % n=14	**Excruciating** % n=10
Mobility	Level 1	1.9±0.8, 1-3, 2	0	12	5.4	5.6	0	0
	Level 2	2.4±0.9[3], 1-5, 2	100	68	85.7	77.8	85.7	80
	Level 3	2.4±1.2, 1-5, 2	0	28	8.9	16.7	14.3	20
Self-Care	Level 1	2.2±1.1, 0-5, 2	100	60	46.4	38.9	28.6	40
	Level 2	2.5±1.0[1], 1-4, 2	0	32	46.4	50	71.4	40
	Level 3	2.9±0.8, 1-3, 2	0	8	7.1	11.1	0	20
Usual Activities	Level 1	2.1±0.8, 1-4, 2	0	20	19.6	13.9	7.1	0
	Level 2	2.9±0.9[2], 0-5, 2	100	72	67.9	66.7	50	50
	Level 3	2.9±0.9, 1-5, 3	0	8	12.5	19.4	42.9	50
Pain / Discomfort	Level 1	1.8±0.8[1], 1-3, 2	0	8	3.6	2.8	0	0
	Level 2	2.1±0.8, 1-4, 2	100	80	87.5	58.3	42.9	0
	Level 3	3.4±0.9[3], 2-5, 3	0	12	8.9	38.9	57.1	100
Anxiety / Depression	Level 1	1.9±0.7[2], 1-3, 2	0	68	41.1	27.8	14.3	10
	Level 2	2.4±0.8[3], 1-4, 2	100	32	55.4	50	50	60
	Level 3	3.3±0.8[1], 2-5, 3	0	0	3.6	22.2	35.7	30

[1]One outlier eliminated, [2]Two outliers eliminated, [3]Three outliers eliminated.

Abbreviations: PPI, Present Pain Intensity; LBP, Low Back Pain.

Chapter 8; Results: Function

Chapter Brief Table of Contents

A language does not become fixed. The human intellect is always on the march, or, if you prefer, in movement, and languages with it.

Victor Hugo (1802 – 1885) – French writer

8.1 Introduction

The analysis conducted so far has shown a high presence of pain and LBP in people with iSCI and demonstrated how pain can affect the QoL of people living in pain. This chapter aims to answer the primary question "What is the relationship and what are the characteristics between function and LBP in people with iSCI?"

It has been explained previously (Chapter 5) that to collect data about function the SCIM III measurement was used. This measurement was translated into Greek. A preliminary validation of the Greek version of SCIM III was conducted. Data from this group was analysed separately from the rest of the group for reasons explained previously. The first part of this chapter will present this preliminary validation and the results of the Greek group. The second part of this chapter will present the results of the remaining group. The psychometric properties of the English version of SCIM III have also been examined and will be presented in the second half of the current chapter.

8.2 Bonferroni correction

For both the Greek group and the rest of the group in the current chapter the main variables of interest were used in 23 different tests thus the α-level of statistical significance set by Bonferroni was $p \leq 0.002$ (Appendix 8: Table 8.2.1).

Part 1 ; Translation and preliminary validation of GR-SCIM III

8.1.3 Preliminary validation of GR-SCIM III

8.1.3.1 Translation of GR-SCIM III

The methodology followed to translate SCIM III and the justification of the methods pursued was explained in detail in Chapters 4 and 5. A forward and back-translation[27] was conducted and all translators were health-related professionals of Greek origin. In addition a professional translator, with health-related experience was involved in the procedure. The difficulty of translating each question was rated on a 0-10 NRS (0=very easy to translate to 10=the most difficult translation). All translators were residents of the UK for a mean 6.8±2.0 (mean±SD) years thus having a good knowledge of the English language and culture (Appendix 8: Table 8.1.1).

In the forward translation words, usually verbs, were translated from the third person (e.g. "requires") into the passive voice, which is commonly used in Greek (e.g. "απαιτείται"). In general, this was accepted as part of the Greek language culture, and as long as the meaning of the text was not altered it was followed throughout the questionnaire unless it was grammatically wrong to do so. Another change, which was done for both the Greek and English versions of SCIM III, was that verbs in general were changed, where appropriate, from the third person to the first person. This was done because SCIM III was going to be completed by the respondents themselves and it would have been grammatically inappropriate and confusing to self-complete a questionnaire which uses third person language. The major changes that occurred during the translation of SCIM III can be found at Appendix 4. The mean hours required to translate the questionnaire was 4.3±3.1 (mean±SD) and the most difficult questions to translate (mean 6.3 and 6.0 on the 0-10 NRS) were related to "sphincter management" (Table 8.2.1).

[27] For details on forward and back-translation refer to Chapter 4.

There were two volunteer back-translators, who had not participated in the forward translation, both of Greek origin. One translator provided information about the difficulty of translating the questionnaire rated as 6 (0-10 NRS) and needed 4.5 hours to complete the translation. The dictionary was used rarely, and the most difficult question to translate was related to "bladder management". The process of the translation was described in Chapter 4, Figures 4.1, 4.2. The Greek version of SCIM III is at Appendix 3.

8.1.3.2 GR-SCIM III; validity; Principal Component Analysis (PCA)

The original developers of SCIM III tested the unidimensionality of the measure's subscales using factor analysis. Only a negligible fraction of the scale score variance was not explained by ability measurements and this could be due to randomness and not due to any extraneous hidden variable.[65] Unidimensionality was also supported for the UK group when their data were tested in the same study.[171]

In this study, the first step taken was to check the data collected for normality by using matrix scatterplots for each subgroup separately and for the sum variables of the total of the subgroups. The relationship between the variables was checked via a correlation matrix.

PCA was conducted to check for unidimensionality. Table 8.2.2 summarises the main results of PCA including the KMO and Bartlett's tests.[28] None of the KMO test results were below acceptance value (<0.50), though the "respiration" item in the "respiration and sphincter management" subscale was rather low but still acceptable. This means that the data were appropriate for factor analysis. The Bartlett test was significant in all cases meaning that the variables were correlated enough to justify factor analysis. Finally, only one factor was extracted each time confirming the unidimensionality of each of the subscales of the GR-SCIM III.

[28] For details on the theory on PCA, KMO test and Bartlett's test refer back to Chapter 5, Section 5.23.

Table 8.2.2: Principal Component Analysis for GR-SCIM III

Subscales	KMO test[1]	KMO values for individual items	Bartlett's test[2]	Number of factors extracted
Self-care (6 items)	KMO=0.78	>0.66	χ^2 (15)=178.32 **p≤0.001*** **	1
Respiration & sphincter management (4 items)	KMO=0.55	>0.55[3]	χ^2 (6)=33.36 **p≤0.001*** **	1
Mobility in room & toilet (3 items)	KMO=0.67	>0.60	χ^2 (3)=137.07 **p≤0.001*** **	1
Mobility indoors & outdoors (6 items)	KMO=0.89	>0.85	χ^2 (15)=319.72 **p≤0.001*** **	1
Sum of all 4 subscales (4 items)	KMO=0.80	>0.77	χ^2 (6)=92.16 **p≤0.001*** **	1

[1] Values for KMO are: <0.5 not accepted, 0.7 – 0.8 good, 0.8 – 0.9 excellent, >0.9 superb, [2] Bartlett's test needs to be <0.05, [3] The item of "respiration" was <0.55 (0.42),
in bold: *** Significant at p≤0.001 level.
Statistical Tests: χ^2, Bartlett's Chi square; KMO, Kaiser-Meyer-Olkin

8.1.3.3 GR-SCIM III; criterion/concurrent validity

Criterion/concurrent validity was examined for two of the subscales of SCIM (self-care and mobility) by correlating them with the same two subscales of EQ-5D (self-care and mobility). The two tests are scored in opposite directions, i.e. in EQ-5D the higher the score the worse the health outcome whereas in SCIM the higher the score the better the outcome. Therefore the two measures should be inversely (negatively) related to indicate a good concurrent validity and the closer this relationship to -1 the better the relationship.

Applying Spearman's ρ correlation[29], on the data of 45 people who responded to the two subscales of both the measures, the correlation between the self-care subscales was found to be strong ρ=-0.78 and between the mobility subscales it was moderate ρ=-0.58. In both occasions these correlations were statistically significant at p≤0.01 level.

[29] Spearman's ρ was used because one variable was on a continuous and one on an ordinal level of measurement.

8.1.3.4 GR-SCIM III; reliability; internal consistency

Since the unidimensionality of the subscales of GR-SCIM III were established, internal consistency was tested which would help to examine reliability. Cronbach's α_{30} was used for each subscale and for the sum of the subscales.

In particular, for the "self-care" subscale, Cronbach's α was found to be α=0.90, which is "excellent". The item of "feeding" within this subscale was the weakest item (α=0.54) and if this item was to be deleted then Cronbach's α for the subscale would increase to α=0.91 (Table 8.2.3). For the "respiration and sphincter management" subscale, Cronbach's α was found to be α=0.59, which is a "poor" correlation. Within this subscale two items had below acceptable level correlations; "respiration" (α=0.17) and "bowel management" (α=0.39) and if deleted then Cronbach's α would increase to α=0.65 and α=0.51. For the "mobility in the room and toilet" subscale, Cronbach's α was α=0.83, which was a "good" correlation. The item of "mobility in bed" in this subscale had the lowest correlation (α=0.73) and if deleted then Cronbach's α would increase to α=0.98. For the "mobility indoors and outdoors" subscale, Cronbach's α was α=0.91, which was "excellent". The item "transfer ground-wheelchair" within this subscale was the lowest (α=0.77) and, if deleted, Cronbach's α would increase to α=0.92. Overall, Cronbach's α for the GR-SCI III was α=0.78 which is "acceptable". The subscale of "respiratory & sphincter management" was the weakest subscale within the total GR-SCIM III which rated as "poor" (α=0.57) and if deleted Cronbach's α of the total scale would increase to α=0.74. Finally, the subscales of "self-care" and "mobility indoors & outdoors", were the strongest subscales and, if deleted, the α for the total scale would drop (Table 8.2.3).

Examining the results, ceiling effects$_{31}$ were noticed. Of the 19 items included in the four subscales 11 had a ceiling effect (57.9%). Of the four subscales one had a ceiling effect of 20%. The subscale with the highest ceiling effect was the "mobility in room and toilet" (100%) followed by "respiration & sphincter management" (75%), "self-

[30] For a reminder on the theory of Cronbach's α refer back to Chapter 5, Section 5.23.1.

[31] Ceiling and floor effect is the percentage of the sample achieving the highest and lowest possible scores, respectively.[293]

care" (66%) and finally "mobility indoors & outdoors" (16.7%) (Table 8.2.4). Floor effect was 0%.

To summarise the above, PCA verified the unidimensionality of the GR-SCIM III which is in line with the unidimensionality of the original English version of SCIM III.[64] Criterion/concurrent validity was tested by examining two subscales of SCIM III with two subscales of EQ-5D and it was found to be strong for "self-care" (ρ=-0.78) and moderate for the "mobility" subscale (ρ=-0.58). Finally, in GR-SCIM III all items correlated well with the subscales they were under and the tool had acceptable internal consistency, α=0.78, with the subscales ranging from 0.59 – 0.91.

Table 8.2.3: Cronbach's alpha for GR-SCIM III

Item	Item total correlation[1]	Cronbach's alpha if item deleted[2]
Self-care subscale α=0.90		
Feeding	0.54	0.91
Bathing upper body	0.77	0.88
Bathing lower body	0.86	0.86
Dressing upper body	0.86	0.86
Dressing lower body	0.80	0.88
Grooming	0.73	0.88
Respiration & sphincter management α=0.59		
Respiration	0.17	0.65
Bladder management	0.51	0.44
Bowel management	0.39	0.51
Use of toilet	0.65	0.38
Mobility in room & toilet α=0.83		
Mobility in bed	0.73	0.98
Transfer bed-wheelchair	0.86	0.70
Transfer wheelchair-toilet-tub	0.84	0.72
Mobility indoors & outdoors α=0.91		
Mobility indoors	0.94	0.86
Mobility moderate distances	0.96	0.86
Mobility outdoors	0.92	0.87
Stair management	0.90	0.88
Transfer wheelchair-car	0.79	0.91
Transfer ground-wheelchair	0.77	0.92
Sums of subscales α=0.78		
Self-care	0.73	0.69
Respiration & sphincter management	0.57	0.74
Mobility room & toilet	0.76	0.78
Mobility indoors & outdoors	0.77	0.68

[1]Item total correlation is the correlation between each item and the total score or the subscale.
[2]This is how much the value of alpha would change if the particular item was deleted from the analysis. No items have been deleted in GR-SCIM III.

Table 8.2.4: Description of items and subscales of GR-SCIM III

Task	n	Mean	SD	Median	Min - Max
Feeding	45	2.8	0.5	3	1 -3
Bathing upper body	41	2.2	0.9	2	0 – 3
Bathing lower body	45	2.0	1.0	2	0 – 3
Dressing upper body	45	2.3	1.3	3	0 – 4
Dressing lower body	45	2.6	1.5	3	0 – 4
Grooming	44	2.7	1.4	3	0 – 3
Total self-care [1]	45	14.5	5.1	16	2 – 20
Respiration	45	10.0	0.3	10	8 – 10
Sphincter management - bladder	43	13.6	3.5	15	0 – 15
Sphincter management – bowel	44	7.9	2.9	8	0 – 10
Use toilet	43	3.8	1.8	5	0 – 5
Total respiration & sphincter management [2]	45	34.3	7.5	38	11 – 40
Mobility in bed	45	5.2	1.4	6	0 – 6
Transfer bed – wheelchair	40	1.6	0.7	2	0 – 2
Transfer wheelchair – toilet – tub	43	1.6	0.6	2	0 – 2
Total Mobility in room & toilet [3]	45	8.2	2.5	10	0 – 10
Mobility indoors	45	5.6	2.6	6	0 – 8
Mobility moderate distance	43	5.2	2.7	6	0 – 8
Mobility outdoors	44	4.7	2.6	6	0 – 8
Stair management	44	1.8	1.3	2	0 – 3
Transfer wheelchair - car	44	1.6	0.7	2	0 – 3
Transfer ground – wheelchair	44	0.7	0.5	1	0 – 1
Total mobility indoors & outdoors [4]	45	19.0	9.9	23	0 – 30
Total SCIM [5]	45	76.1	21.3	82	28 - 100

[1]Score can range from 0-20, [2]Score can range from 0-40, [3]Score can range from 0-10, [4]Score can range from 0-30, [5]Score can range from 0-100.
Abbreviation: SCIM, Spinal Cord Independence Measure.

8.1.4 GR-SCIM III; general results

The possible range of scores for each SCIM subscale is different thus, to understand on which subscale people reported better function, the percentage of the group mean score for each subscale in relation to its maximum score for the subscale was calculated. The group scored better on the “respiration and sphincter management” subgroup, followed by the “mobility” subscale and last the “self-care” subscale. Within the mobility subscale the group scored better on the “mobility in room and toilet” subscale followed by the “mobility indoors and outdoors”.

GR-SCIM III was completed by 45 people, more than half were males (56.1%), 25% of people had finished high school education in Greece (12 years of education), 31.5% had finished the third level of education (University or Technological Educational Institution (TEI)) and nearly 7% had completed postgraduate studies. Mean age of respondents was 60.9±17.4 (mean±SD) years and mean time since injury was 11.0±8.6 (mean±SD) years. Two-thirds of the respondents (66.7%) had paraplegia, primarily had suffered a non-traumatic iSCI (60%), and more than half were married or in a relationship (Table 8.2.5).

8.1.5 GR-SCIM III; relation to demographic profile characteristics

Overall, females (n=18) reported slightly higher (better) SCIM scores than males (n=23) for all subscales apart from "mobility in room and toilet". Following testing for differences, no statistically significant results were found between the two sexes and their total function (Table 8.2.6; Appendix 8: Table 8.3.1). People with a non-traumatic cause of injury (n=27) had slightly better function than people with a traumatic injury (n=18), but the differences were not significant (Table 8.2.6; Appendix 8, Table 8.3.3).

Data showed that the correlation between age and SCIM was positive, of small to moderate strength for all subscales, but not statistically significant (Table 8.2.6; Appendix 8: Figure 8.3.1). The correlation between time since injury and total SCIM or its subscales was negative and weak (the longer the time since injury the better the function) but not significant (Table 8.2.6). Because older age correlated with time since injury (p=0.005, r=0.41, Pearson's correlation) the correlation between age and function was tested controlling for time since injury using partial correlation. The strength of the correlations became slightly stronger and in the case of "mobility in room and toilet" the result passed the Bonferroni α-level of significance (Table 8.2.6).

Table 8.2.5: Demographics of the Greek group

Variable	Mean ± SD, % or min-max
Sex (M/F) (%) (n=41)	56.1/43.9
Age (years, mean ± SD, min-max) (n=45)	60.9 ± 17.4, 26.5-91.7
Age groups (%) (n=45)	4.4
18 - 29	11.1
30 – 39	8.9
40 – 49	20.0
50 – 59	17.8
60 – 69	37.8
70+	
Time since injury (years, mean ± SD, min-max) (n=45)	11.0 ± 8.6, 1.4- 34.3
Age at injury (years, mean ± SD, min-max) (n=45)	50.9 ± 15.9, 20.8-78.3
Type of injury (%) (n=45)	
Incomplete Tetraplegia	33.3
Incomplete Paraplegia	66.7
Level of injury (%) (n=45)	
Cervical	33.3
Thoracic	35.6
Lumbar	31.1
Cause of Injury (%) (n=45)	
Traumatic	40
Non-Traumatic	60
Ethnic group (%) (n=45)	100
White – Greek	
Mother Tongue (%) (n=45)	97.8
Greek	2.2
English	
Marital status (%) (n=43)	
Married	53.5
Living with partner	9.3
In a relationship	4.7
Widowed	20.9
Single	11.6
Education (%) (n=44)	6.8
Master's	31.8
University Bachelor Degree	2.3
College or equivalent	25.0
High School	34.1
No diploma/degree	
Employment (%)[1] (n=45)	
Employed	15.5
Self-employed	22.2
Voluntary work	2.2
Receive health benefits	4.4
Unable to work due to iSCI	8.9
Homemaker	2.0
Retired	23.0
Other	2.2
Working hours per week (n=1)	40.0

[1] Total sums greater than 100% because respondents were allowed to choose more than one option.

Overall, it was noticed that people with paraplegia (n=30) reported a better mean function for all subscales and total SCIM than people with tetraplegia (n=15) but the differences were not significant (Table 8.2.6; Appendix 8: Table 8.3.4). This was also confirmed when the three different levels of injury (cervical, thoracic and lumbar) were examined (Table 8.2.6; Appendix 8: Table 8.3.5).

Time since injury did not correlate significantly with any of the function subscales (Table 8.2.6). When the correlations between function and time since injury were re-calculated while controlling for age, it was noticed that the relationships became stronger but still not statistically significant (Table 8.2.6).

8.1.6 GR-SCIM III; relation to pain, MSKP and LBP

Part of the first hypothesis theme was to examine the relation between the presence of the categories of pain and function:

Hypothesis 0 (null): In people with iSCI there is no significant difference in function (total SCIM or subscales) between those with and without pain, MSKP or LBP.

Hypothesis 3a: In people with iSCI there is a significant difference in function (total SCIM or subscales) between those with and without pain.

Hypothesis 3b: In people with iSCI there is a significant difference in function (total SCIM or subscales) between those with and without current LBP.

Hypothesis 3c: In people with iSCI there is a significant difference in function (total SCIM or subscales) between those with and without MSKP.

People without pain (n=10) and without MSKP (n=25) reported slightly higher mean total SCIM (better function) than people with pain (n=35) or MSKP (n=17) (Table 8.2.7). However, interestingly, people with LBP (n=30) reported slightly better total function than those without LBP (n=13) but the difference was not significant (p=0.67, t=-0.42, 95% CI -17.5, 11.5, ES: d=0.14, Table 8.2.7, Figure 8.2.1; Appendix 8: Table 8.4.1).

Table 8.2.6: Summary of statistics between GR-SCIM III and demographic profile characteristics

	Self-care subscale	Respiration & sphincter management	Mobility room & toilet	Mobility indoors & outdoors	Total SCIM
Gender	t=-0.51, df172 p=0.60 95% CI -2.23, 1.30	t=1.75, df171 p=0.08 95% CI -0.24, 4.23	t=-1019, df172 p=0.23 95% CI -1.61, 0.39	t=0.74, df172 p=0.45 95% CI -1.65, 3.65	t=0.69, df171 p=0.48 95% CI -4.07, 8.50
Cause of injury	U=2103.5 p=0.10	t=-0.25, df170 p=0.79 95% CI -2.99, 2.30	U=2497.5 p=0.88	t=0.05, df172 p=0.95 95% CI -3.03, 3.21	U=2411.5 p=0.89
Age	r=0.23 p=0.12	r=0.18 p=0.23	r=0.29 p=0.04[1]	r=0.37 p≤0.01[1]	r=0.33 p=0.02[1]
Age (after controlling for time since injury)	r=0.28 p=0.06 n=42	r=0.32 p=0.02[1]	r=0.36 p=0.016[1]	r=0.45 **p=0.002****	r=0.43 p=0.003[1]
Type of injury	U=152 p=0.07	U=166.5 p=0.26	U=194.5 p=0.41	U=185 p=0.33	U=144.5 p=0.09
Time since injury	ρ=-0.05 p=0.71	r=-0.25 p=0.08	ρ=-0.05 p=0.72	ρ=-0.06 p=0.06	r=-0.14 p=0.33
Time since injury (after controlling for age)	r=-0.17 p=0.25 n=42	r=-0.37 p=0.013[1]	r=-0.22 p=0.14	r=-0.28 p=0.06	r=-0.33 p=0.02[1]

[1]not significant post Bonferroni correction; **Significant at p≤0.01 level, **in bold**: significant following application of the Bonferroni correction.
Abbreviation: SCIM, Spinal Cord Independence Measure.
Statistical tests: t, Independent t-test; U, Mann-Whitney U test; r, Pearson's correlation; ρ, Spearman's rank correlation rho.

In Chapter 6 (Section 6.1.7), prior to application of the Bonferroni correction a higher proportion of females reported having MSKP. Taking into account the report by IASP[177] to investigate pain-related variables by gender the difference in function in people who feel and those who do not feel MSKP was tested in males and females. This was not part of the main analysis and as such it is presented at Appendix 8, Table 8.3.2.

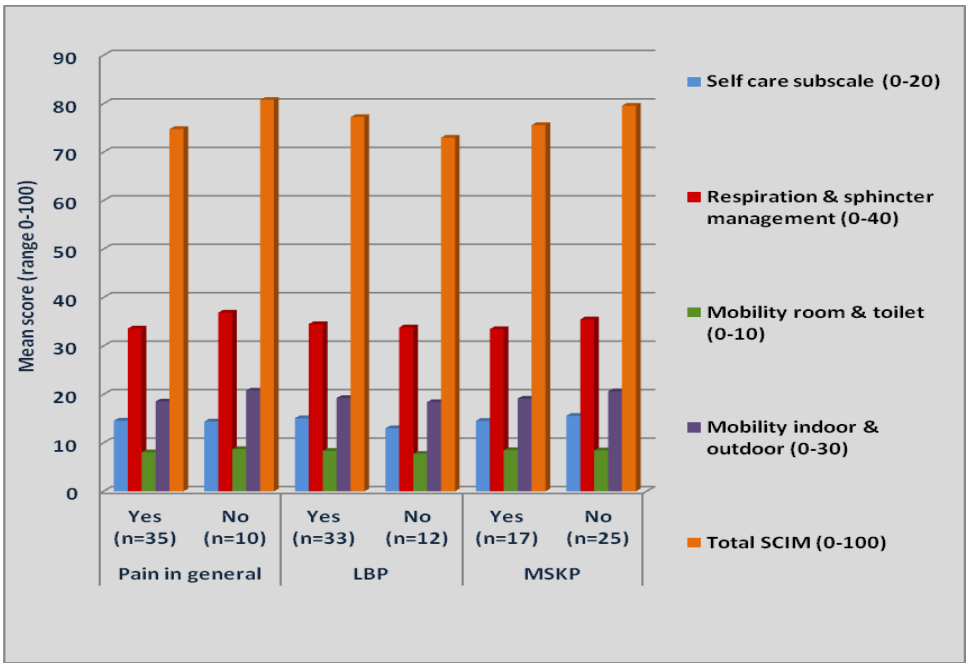

Figure 8.2.1: Mean SCIM scores reported by people with and without pain, LBP and MSKP.
Abbreviation: SCIM, Spinal Cord Independence Measure; LBP, Low Back Pain; MSKP, Musculoskeletal Pain.

Table 8.2.7: Statistical differences on function scores between people with and without pain, MSKP or LBP

	Self-care subscale	Respiration & sphincter management	Mobility room & toilet	Mobility indoors & outdoors	Total SCIM
Pain	t=-0.09, df43 p=0.92 95%CI -3.9, 3.6 ES: d=0.04	U=163.5 p=0.75 ES: r=0.09	t=0.72, df43 p=0.47 ES: d=0.26 95%CI -1.1, 2.4 U=157.5, p=0.59	t=0.63, df43 p=0.53 ES: d=0.24 95%CI -4.9, 9.4 U=162, p=0.72	U=169 p=0.87 ES: r=0.02
Current LBP	t=-0.85, df41 p=0.39 95% CI -5.0, 2.0 ES: d=0.29	U=122.5 p=0.28 ES: r=0.18	t=-0.58, df41 p=0.55 95%CI -2.1, 1.15 ES: d=0.19 U=184.5, p=0.75	t=-1.8, df41 p=0.85 95%CI -7.1, 5.9 ES: d=0.06 U=184, p=0.77	t=-0.42, df41 p=0.67 95%CI -17.5, 11.5 ES: d=0.14
MSKP	t=0.71, df39 p=0.48 95% CI -1.9, 4.0 ES: d=0.22	U=208 p=0.90 ES: r=0.02	t=-0.04, df40 p=0.96 95%CI -1.4, 1.3 ES: d=0.04 U=206, p=0.85	U=210 p=0.94 ES: r=0.009	t=0.61, df44 p=0.54 95%CI -9.2, 17.2 ES: d=0.18

Abbreviations: SCIM, Spinal Cord Independence Measure, LBP, Low Back Pain; MSKP, Musculoskeletal Pain.
Statistical tests: t, Independent t-test; U, Mann-Whitney U test; r, Pearson's correlation; ρ, Spearman's rank correlation rho.

8.1.7 GR-SCIM III; relation to pain/LBP days, free weeks, onset

When people were divided into groups based on the number of days they felt pain/LBP some groups contained only a few respondents. In order to increase the reliability of the statistical tests to be used, the groups were collated into two larger sized categories: 1) 1-20 days of pain/LBP days felt per month and 2) 21 – every day pain/LBP felt per month. Analysis showed that an increasing number of pain or LBP days did not correlate significantly with function. However, the strength of all the correlations were strong and had strong effect sizes, thus failure to find statistical results may have been due to the small number of respondents even in these groups (Appendix 8: Tables 8.5.1 and 8.5.2).

The group of people divided according to the frequency of pain/LBP-free breaks were also collated into larger categories: 1) have pain/LBP-free break most of the time, frequently or sometimes, and 2) do not often have a pain/LBP-free break, rarely and always in pain (Appendix 8: Table 8.5.3). Following analysis no statistical correlations were found between the frequency of pain or LBP breaks and function. However, the effect sizes were mostly large indicating a possible practical significance (Appendix 8: Table 8.5.4).

The second hypothesis theme examined the relation between pain/LBP onset and function:

Hypothesis 0 (null): In people with iSCI there is no significant correlation between function (total SCIM or subscales) and the onset of pain or LBP post iSCI.

Hypothesis 7a: In people with iSCI there is a significant correlation between function (total SCIM or subscale) and the onset of pain post iSCI.

Hypothesis 7b: In people with iSCI there is a significant correlation between function (total SCIM or subscale) and the onset of LBP post iSCI

To avoid having very small groups, time of pain/LBP onset were collated into two larger categories; a) pain/LBP onset immediately after or within one month post iSCI and b) pain/LBP onset after one month post injury. Overall, it seemed that people with

pain (n=19) or LBP (n=20) onset after six months post iSCI had slightly better function on SCIM than people who had pain (n=14) or LBP (n=13) onset within the first month post iSCI (Tables 8.2.8 and 8.2.9). The correlations were not statistically significant but all were strong. Consequently, if only the statistical significance is taken into account then this would lead to the acceptance of the null hypothesis (with the exception of LBP onset and "mobility indoors and outdoors"). However, the strength of the correlations must be considered too. In the case of "mobility in room & toilet" those people whose LBP onset was more than one month post iSCI had better scores than those with onset within the first month post iSCI ($p \leq 0.001$, $\phi = 0.75$, Phi Test) (Table 8.2.9).

Table 8.2.8: Mean function scores based on the onset of pain and LBP following iSCI

	Pain onset		**LBP onset**	
	Immediately after and up to 1 month post iSCI (n=14) mean±SD, median, min-max	**After 1 month post iSCI** (n=19) mean±SD, median, min-max	**Immediately after and up to 1 month post iSCI** (n=13) mean±SD, median, min-max	**After 1 month post iSCI** (n=18) mean±SD, median, min-max
Self-care subscale Range 0-20	13.6±6.5 16.5, 2-20	15.4±726.0 17, 4-20	14.4±5.9 17, 4-20	15.3±5.2 17, 2-20
Respiration & sphincter management Range 0-40	35.8±6.1[1] 38, 18-40	32.7±9.5 38, 11-40	35.8±6.3[1] 38, 18-40	35.4±7.1 38, 15-40
Mobility room & toilet Range 0-10	7.7±2.3 8, 4-10	8.4±2.8 10, 0-10	8.0±2.2 8, 4-10	9.4±1.4[2] 10, 6-10
Mobility indoors & outdoors Range 0-30	17.6±11.3 23, 0-30	20.5±9.3 26, 4-30	18.5±11.2 23, 0-30	21.2±9.0 26, 5-30
Total SCIM Range 0-100	74.1±23.3 82.5, 28-100	77.0±24.2 90, 34-99	76.0±21.1 83.5, 27-98	80.0±21.3[3] 89, 28-100

Table excludes people with no pain or who did not recall onset of pain, [1]1 outlier eliminated, [2]Two outliers eliminated, [3]Three outliers eliminated.
Abbreviations: SCIM, Spinal Cord Independence Measure, LBP, Low Back Pain.

Table 8.2.9: Statistical correlations between function and time of pain/LBP onset

	Self-care subscale	Respiration & sphincter management	Mobility room & toilet	Mobility indoor & outdoor	Total SCIM
Pain n=33	ϕ=0.79 p=0.64	ϕ=0.85 p=0.46	ϕ=0.40 p=0.71	ϕ=1.02 p=0.25	ϕ=1.23 p=0.38
LBP n=31	ϕ=0.713 p=0.20	ϕ=0.51 p=0.62	ϕ=0.75 **p≤0.001*** ** n=29	ϕ=0.65 p=0.50	ϕ=0.84 p=0.50

***Significant at p≤0.001 level; **In bold**: significant following application of Bonferroni correction.
Abbreviations: SCIM, Spinal Cord Independence Measure, LBP, Low Back Pain.
Statistical test: ϕ test.

8.1.8 GR-SCIM III; relation to pain extent

The number of areas with pain of the body did not correlate significantly with total function or any of its subscales (n=30) (Appendix 8: Table 8.6.1).

8.1.9 GR-SCIM III; relation to quality and intensity of LBP

The third hypothesis theme included the investigation of the relationship between the quality and intensity of LBP with function. It had been hypothesised that:

Hypothesis 0a (null): In people with iSCI there is no significant correlation between function (total SCIM or subscales) and quality (sensory, affective or total PRI) of LBP.

Hypothesis 12a: In people with iSCI there is a significant correlation between function (total SCIM or subscales) and sensory PRI of LBP.

Hypothesis 12b: In people with iSCI there is a significant correlation between function (total SCIM or subscales) and affective PRI of LBP.

Hypothesis 12c: In people with iSCI there is a significant correlation between function (total SCIM or subscale) and total PRI of LBP.

All correlations were found to be very weak, negative and none was statistically significant (Table 8.2.10). The null hypothesis was accepted.

Table 8.2.10: Correlations between quality of LBP (PRI) and function (SCIM)

	Self-care subscale	Respiration & sphincter management	Mobility room & toilet	Mobility indoors & outdoors	Total SCIM
S-PRI n=30	r=-0.11,p=0.50 95%CI -0.18, 0.51	r=-0.06,p=0.72 95%CI -0.26, 0.45	r=-0.13,p=0.47 95%CI -0.36, 0.36	r=-0.06,p=0.74 95%CI -0.11, 0.56	r=-0.09,p=0.61 95%CI -0.17, 0.52
A-PRI n=31	r=-0.07,p=0.70 95%CI -0.19, 0.47	r=0.19,p=0.28 95%CI 0.05, 0.64	r=0.04,p=0.80 95%CI -0.16, 0.50	r=0.06,p=0.71 95%CI -0.02, 0.59	r=0.08, p=0.65 95%CI 0.00, 0.61
Total PRI n=31	r=-0.11,p=0.55 95%CI -0.16, 0.50	r=0.03,p=0.84 95%CI -0.11, 0.53	r=-0.07,p=0.71 95%CI -0.41, 0.27	r=-0.01,p=0.94 95%CI -0.03, 0.59	r=-0.02,p=0.88 95%CI -0.07, 0.56

One outlier had been eliminated.
Abbreviations: SCIM, Spinal Cord Independence Measure; S-PRI, Sensory Pain Rating Index; A-PRI, Affective PRI.
Statistical test: r, Pearson's correlation.

The relationship between intensity of LBP and function was also hypothesised:

Hypothesis 0 (null): In people with iSCI there is no significant correlation between function (total SCIM or subscales) and intensity of LBP.

Hypothesis 13a: In people with iSCI there is a significant correlation between function (total SCIM or subscales) and intensity of current LBP.

Hypothesis 13b: In people with iSCI there is a significant correlation between function (total SCIM or subscales) and intensity of LBP over last one month.

Hypothesis 13c: In people with iSCI there is a significant correlation between function (total SCIM or subscales) and intensity of LBP over last three months.

Hypothesis 13d: In people with iSCI there is a significant correlation between function (total SCIM or subscales) and evaluative LBP intensity.

When intensity of LBP (all time periods) increased the mean function (total and all its subscales) decreased, thus became worse. These correlations were strong and significant in one case; however, the numbers of responses in the groups were

extremely small[32]. This reduces the reliability of the results of this particular analysis. But intensity of LBP could be examined via the evaluative PPI for which data were more complete (Table 8.2.11).

Analysis showed that as the evaluative dimension of LBP increased, function (SCIM and its subscales) mean score decreased. These correlations were moderate and for "self-care", "mobility indoors and outdoors" and total SCIM did not pass the Bonferroni α-level of significance (Table 8.2.11).

Table 8.2.11: Correlations between LBP intensity and function

	Self-care subscale	Respiration & sphincter management	Mobility room & toilet	Mobility indoors & outdoors	Total SCIM
Intensity of current LBP n=3[1]	r=-0.45 p=0.009[1]	r=-0.36 p=0.04[1]	r=-0.34 p=0.05	r=-0.67 **p≤0.001*** **	r=-0.58 p≤0.01[1]
Intensity of LBP last 1 month n=3[1]	ρ=-0.81 p=0.39	ρ=-0.81 p=0.39	ρ=-0.04 p=0.96	ρ=-0.50 p=0.65	ρ=-0.04 p=0.96
Intensity of LBP last 3 months n=3[1]	ρ=-0.71 p=0.49	ρ=-0.89 p=0.29	ρ=0.20 p=0.87	ρ=-0.50 p=0.66	ρ=-0.50 p=0.66
Evaluative PPI n=29	r=-0.41 p=0.02[1] 95%CI -0.71, -0.15	r=-0.12 p=0.51 95%CI -0.46, 0.25	r=-0.13 p=0.47 95%CI -0.24, 0.24	r=-0.23 p=0.22 95%CI -0.54, 0.14	r=-0.41 p=0.02[1] 95%CI -0.71, -0.15

[1]not significant post Bonferroni correction; ***Significant at p≤0.001 level; **in bold**: significant following application of the Bonferroni correction; Confidence Interval cannot be calculated as the group size is very small.
Abbreviations: SCIM, Spinal Cord Independence Measure; LBP, Low Back Pain; PPI, Present Pain Intensity.
Statistical tests: r, Pearson's correlation; ρ, Spearman's rank correlation rho.

8.1.10 GR-SCIM III; relation to QoL

Statistical analysis showed that as function increased (improved), the health classification also improved. These correlations were moderate or strong and they were all statistically significant (Table 8.2.12; Appendix 8: Figure 8.7.1). When function

[32] For an explanation as to why there were few responses from the Greek group refer back to Chapter 6, Section 6.2.7.

improved people also perceived their health status as better. However, it was only when "mobility indoors and outdoors" improved that improvements in the perception of the health status reached a statistically significant level (Table 8.2.12; Appendix 8: Figure 8.7.2).

Table 8.2.12: Correlations between function and QoL

	Self-care subscale	**Respiration & sphincter management**	**Mobility room & toilet**	**Mobility indoors & outdoors**	**Total SCIM**
EQ-5D Index	ρ=0.66	ρ=0.45	ρ=0.60	ρ=0.57	ρ=0.62
n=44	**p≤0.001*** **	**p=0.002** **	**p≤0.001*** **	**p≤0.001*** **	**p≤0.001*** **
EQ-VAS	r=0.40	r=0.11	r=0.18	r=0.46	r=0.37
n=43	p=0.008[1]	p=0.46	p=0.22	**p=0.002** **	p≤0.01[1]

[1]not significant post Bonferroni correction; **Significant at p≤0.01 level, ***Significant at p≤0.001 level; **in bold:** significant following application of the Bonferroni correction.
Abbreviations: SCIM, Spinal Cord Independence Measure; EQ-5D, Quality of life; EQ-VAS, Quality of Life Visual Analogue Scale.
Statistical tests: r, Pearson's correlation; ρ, Spearman's rank correlation rho.

Part 2; Results: SCIM III, function

8.2.1 Introduction

The first part of this chapter dealt with the analysis and preliminary validation of SCIM III. It presented the demographic results of the group as well as examined the relations with the variables of interest. This second part will examine the psychometric properties of SCIM III and examine the functional profile of the group that used the English version of SCIM III. The same question examined in the first part of this chapter will be examined here, too; "What is the relationship and what are the characteristics between function and LBP in people with incomplete SCI?" The Bonferroni α-level of significance is set at p≤0.002.

8.2.2 Validation of SCIM III; for use by self-completion

8.2.2.1 SCIM III; validity; Principal Component Analysis (PCA)

The English version of SCIM III used in this study was also examined for its validity and reliability because it was used under different conditions than those for which it was originally developed (by self-completion). PCA was done to examine the unidimensionality of the English version of SCIM III which was confirmed as only one factor was extracted each time (Table 8.2.2.1). All KMO test results were above acceptance value (>0.50) indicating that data were appropriate for factor analysis. Variables were also correlated enough to justify factor analysis (Table 8.2.2.1).

Table 8.2.2.1: Principal Component Analysis of the English version of SCIM III

Subscales	KMO test[1]	KMO values for individual items	Bartlett's test[2]	Number of factors extracted
Self-care (6 items)	KMO=0.89	>0.86	χ^2=897.7 **p≤0.001*** **	1
Respiration & sphincter management (4 items)	KMO=0.60	>0.58	χ^2=48.6 **p≤0.001*** **	1
Mobility in room & toilet (3 items)	KMO=0.73	>0.67	χ^2=441.3 **p≤0.001*** **	1
Mobility indoors & outdoors (6 items)	KMO=0.85	>0.79	χ^2=794.6 **p≤0.001*** **	1
Sum of all 4 subscales (4 items)	KMO=0.75	>0.68	χ^2=375.9 **p≤0.001*** **	1

[1] Values for KMO are: <0.5 not accepted, 0.7 – 0.8 good, 0.8 – 0.9 excellent, >0.9 superb, [2] Bartlett's test needs to be <0.05, **in bold:** ***Significant at p≤0.001 level
Statistical Test: KMO, Kairer Meyer Olkin test; χ^2, Bartlett's Chi square

8.2.2.2 SCIM III; criterion/concurrent validity

Criterion concurrent validity was examined by checking the correlations between two of the subscales of SCIM ("self-care" and "mobility") with two similar of the subscales of EQ-5D ("self-care" and "mobility"). The two tests are scored in opposite directions thus they should be inversely (negatively) correlated to indicate a good concurrent validity (the closer to -1 the better). Applying Spearman's ρ_{33} the correlations were found to be highly significant and of moderate to large strength; between the "self-care" subscales the correlation was strong: ρ=-0.75, p≤0.001, n=156, and between the "mobility" subscales it was moderate: ρ=-0.45, p≤0.001, n=156.

8.2.2.3 SCIM III; reliability; internal consistency

Similar to the procedure followed for the GR-SCIM, Cronbach's α was used to examine internal consistency as part of testing for reliability.

[33] Spearman's ρ was used because one variable was on a continuous and the other on an ordinal level of measurement.

Overall, Cronbach's α for the English version of SCIM III was very similar to the one found for the Greek version (α=0.79). Some differences were noted in the α of the subscales (see Table 8.2.3). The "self-care" subscale was α=0.92, which was marked as "excellent" and was slightly higher than that found for GR-SCIM III. The item of "feeding" was the weakest within the subscale, similar to GR-SCIM III, but it was not as low as in GR-SCIM III. The "respiration and sphincter management" subscale had an α which was below an acceptable level (α=0.40 and the non-acceptable level is <0.50[164]). "Bowel management" was the weakest item within the subscale (α=0.19) which, if deleted, would increase α to α=0.39 which was still not above acceptable level. The subscale of "mobility in room and toilet" was acceptable α=0.77, with no item falling below acceptable levels. The subscale of "mobility indoors and outdoors" had a slightly smaller α compared to GR-SCIM III, which was still good α=0.87. The weakest item in the subscale was "transfer ground – wheelchair", which was just above acceptable level (α=0.52) and was the weakest item in GR-SCIM III but with a higher Cronbach's (α=0.77). Finally, when examining the sum of the subscales, two out of the four subscales had Cronbach's α of acceptable levels and two of poor levels (Table 8.2.2.2).

Ceiling effects were noticed in the results; of the 19 items included in the four subscales, seven had a ceiling effect (36.8%) which was lower than that found in the case of the Greek group. Of the four subscales, one had a ceiling effect of 20%. "Self-care" and "mobility in room and toilet" were the subscales with the highest ceiling effects (66.6%), followed by "mobility indoors and outdoors" (16.6%). No ceiling effect was noticed for "respiration and sphincter management" and no floor effects were noticed for any item (Table 8.2.2.3).

Table 8.2.2.2: Cronbach's alpha for the English version of SCIM III

Item	Item total correlation[1]	Cronbach's alpha if item deleted[2]
Self-care subscale α=0.92		
Feeding	0.68	0.92
Bathing upper body	0.84	0.90
Bathing lower body	0.86	0.89
Dressing upper body	0.88	0.89
Dressing lower body	0.87	0.90
Grooming	0.76	0.91
Respiration & sphincter management α=0.40		
Respiration	0.28	0.37
Bladder management	0.26	0.38
Bowel management	0.19	0.37
Use of toilet	0.42	0.25
Mobility in room & toilet α=0.77		
Mobility in bed	0.78	0.94
Transfer bed-wheelchair	0.84	0.66
Transfer wheelchair-toilet-tub	0.83	0.65
Mobility indoors & outdoors α=0.87		
Mobility indoors	0.87	0.81
Mobility moderate distances	0.90	0.80
Mobility outdoors	0.75	0.83
Stair management	0.86	0.84
Transfer wheelchair-car	0.61	0.87
Transfer ground-wheelchair	0.52	0.88
Sums of subscales α=0.79		
Self-care	0.73	0.68
Respiration & sphincter management	0.59	0.75
Mobility room & toilet	0.77	0.75
Mobility indoors & outdoors	0.59	0.78

[1]Item total correlation is the correlation between each item and the total score of the subscale.
[2]This is how much the value of alpha would change if the particular item was deleted from the analysis.

Table 8.2.2.3: Descriptive characteristics of SCIM subscales and items

Task	N	Mean	SD	Median	Min – Max of group
Feeding	174	2.6	0.6	3	0 -3
Bathing upper body	172	2.1	0.9	2	0 – 3
Bathing lower body	169	2.0	1.0	2	0 – 3
Dressing upper body	173	3.0	1.4	4	0 – 4
Dressing lower body	170	2.9	1.5	4	0 – 4
Grooming	174	2.5	0.9	3	0 – 3
Total self-care [1]	174	15.1	5.7	18	0 – 20
Respiration	174	9.9	1.2	10	0 – 19
Sphincter management - bladder	172	9.9	4.9	11	0 – 15
Sphincter management – bowel	173	6.0	3.4	8	0 – 10
Use of toilet	173	3.5	1.8	4	0 – 6
Total respiration & sphincter management [2]	174	29.1	7.5	30	0 – 40
Mobility in bed	174	4.9	2.0	6	0 – 6
Transfer bed – wheelchair	172	1.6	0.7	2	0 – 2
Transfer wheelchair – toilet – tub	174	1.5	0.7	2	0 – 2
Total Mobility room & toilet [3]	174	7.9	3.2	10	0 – 10
Mobility indoors	173	3.9	2.5	2	0 – 8
Mobility moderate distance	173	3.6	2.5	2	0 – 8
Mobility outdoors	173	2.9	2.3	2	0 – 8
Stair management	173	1.2	1.1	2	0 – 3
Transfer wheelchair - car	173	1.4	0.7	2	0 – 2
Transfer ground – wheelchair	173	0.6	0.6	1	0 – 6
Total mobility indoors & outdoors[4]	174	13.5	8.5	11	0 – 30
Total mobility[5]	174	21.4	10.7	21	0 – 40
Total SCIM[6]	174	65.5	20.6	68	3 – 100

[1]Score can range from 0-20, [2]Score can range from 0-40, [3]Score can range from 0-10, [4]Score can range from 0-30, [5]Score can range from 0-40, [6]Score can range from 0-100

8.2.3 SCIM III; general results

A total of 174 people completed the English version of SCIM III and the mean score of total SCIM was 65.5±20.6 (mean±SD). To understand on which subscale people reported better function the percentage of the group for each subscale in relation to its maximum mean for the subscale was calculated. The group scored better on “self-care”, followed by “respiration and sphincter management” and least well on the “mobility” subscale. Within the mobility subscale, the group scored higher on the “mobility in room and toilet” subscale followed by “mobility indoors and outdoors”.

8.2.4 SCIM III; relation to demographic profile characteristics

SCIM III (English version) was completed by 111 males and 63 females and despite males reporting slightly better function than females no significant differences were found (Table 8.2.4.1; Appendix 8: Table 8.8.1). This finding concurs with the finding for the Greek respondents that no significant differences were found, although, in the Greek group, females reported slightly better function.

People with a non-traumatic injury (n=37) reported better function scores than people with a traumatic injury (n=137) but differences were not significant as in the Greek group (Table 8.2.4.1; Appendix 8: Table 8.8.3).

Overall, people with paraplegia (n=116) reported better function than people with tetraplegia (n=103) and this difference was significant for "self-care" ($p \leq 0.001$, t=-592, independent t-test), "mobility room and toilet" ($p \leq 0.001$, t=-5.35), and total SCIM ($p \leq 0.001$, t=-3.97) (Table 8.2.4.1; Appendix 8: Table 8.8.4). Analysis was done for the three levels of injury (cervical, thoracic and lumbar), which showed significantly better "self-care" for people with thoracic and lumbar injuries compared with those with cervical injuries (Appendix 8: Tables 8.8.5 and 8.8.6).

It was seen that as age increased, function slightly improved but results did not pass the Bonferroni α-level of significance (Table 8.2.4.1). Though the relationships were not significant, the strength was often moderate and in the case of "mobility in room and toilet" it was large (r=0.99). As there is a significant correlation between time since injury and age ($p \leq 0.01$, r=0.20, n=173) the relation between age and function was checked again while controlling for time since injury. It was found that the correlations remained non-statistically significant, the strength of the correlations became very small and the direction of the correlations changed. When controlling for the time since injury, ageing correlated with a decline in function but not strongly.

Time since injury had a weak, non-significant, negative correlation with function, including all its subscales. This did not change when the age of the participants was controlled for (Table 8.2.4.1).

Table 8.2.4.1: Statistical differences and correlations between function and demographic profile characteristics

	Self-care subscale	Respiration & sphincter management	Mobility room & toilet	Mobility indoors & outdoors	Total SCIM
Gender	t=-0.51, df172 p=0.60 95% CI -2.23, 1.30	t=1.75, df171 p=0.08 95% CI -0.24, 4.23	t=-1019, df172 p=0.23 95% CI -1.61, 0.39	t=0.74, df172 p=0.45 95% CI -1.65, 3.65	t=0.69, df171 p=0.48 95% CI -4.07, 8.50
Cause of injury	U=2103.5, p=0.10	t=-0.25, df170 p=0.79 95% CI -2.99, 2.30	U=2497.5, p=0.88	t=0.05, df172 p=0.95 95% CI -3.03, 3.21	U=2411.5, p=0.89
Age n=166	r=0.23 p=0.12	r=0.18 p=0.23	r=0.99 p=0.04[1]	r=0.37 p≤0.01[1]	r=0.33 p=0.02[1]
Age (after controlling for time since injury)	r=-0.10 p=0.18 n=162	r=-0.10 p=0.16	r=-0.04 p=0.57	r=0.05 p=0.46	r=-0.05 p=0.50
Type of injury	t=-5.92, df216 **p≤0.001*** ** 95% CI -5.5, -2.7	t=-1.12, df216 p=0.26 95% CI -3.17, 0.87	t=-5.35, df212 **p≤0.001*** ** 95% CI -2.9, 1.9 U=4223, **p≤0.001*** **	t=-2.04, df217 p=0.04 95% CI -4.9, 0.09	t=-3.97, df214 **p≤0.001*** ** 95% CI -16.35, -5.5
Time since injury n=173	ρ=-0.05 p=0.46	r=-0.03 p=0.64	ρ=-0.04 p=0.51	ρ=-0.18 p≤0.01[1]	r=-0.17 p=0.02[1]
Time since injury (after controlling for age)	r=-0.08 p=0.29 n=162	r=-0.01 p=0.83	r=-0.05 p=0.48	r=-0.17 p=0.028[1]	r=-0.10 p=0.17

[1]not significant post Bonferroni correction;***Significant at p≤0.001 level; **in bold:** significant following application of the Bonferroni correction.
Abbreviations: SCIM, Spinal Cord Independence Measure.
Statistical tests: r, Pearson's correlation; ρ, Spearman's rank correlation rho; t, independent t-test.

8.2.5 SCIM III; relation to pain, LBP and MSKP

At the onset of the study it had been hypothesised that people with and without the categories of pain would differ on their functional independence scores:

Hypothesis 0 (null): In people with iSCI there is no significant difference in function (total SCIM or subscales) between those with and without pain, MSKP or current LBP.

Hypothesis 3a: In people with iSCI there is a significant difference in function (total SCIM or subscales) between those with and without pain.

Hypothesis 3b: In people with iSCI there is a significant difference in function (total SCIM or subscales) between those with and without MSKP.

Hypothesis 3c: In people with iSCI there is a significant difference in function (total SCIM or subscales) between those with and without current LBP.

In all comparisons conducted people without pain, or current LBP or MSKP reported worse function than people with pain, MSKP or LBP (Figure 8.2.5.1). The correlations did not pass the Bonferroni α-level of significance. In general the effect sizes were small thus not indicating a practical significance either (Table 8.2.5.1; Appendix 8: Table 8.9.1). Consequently, the null hypothesis cannot be rejected.

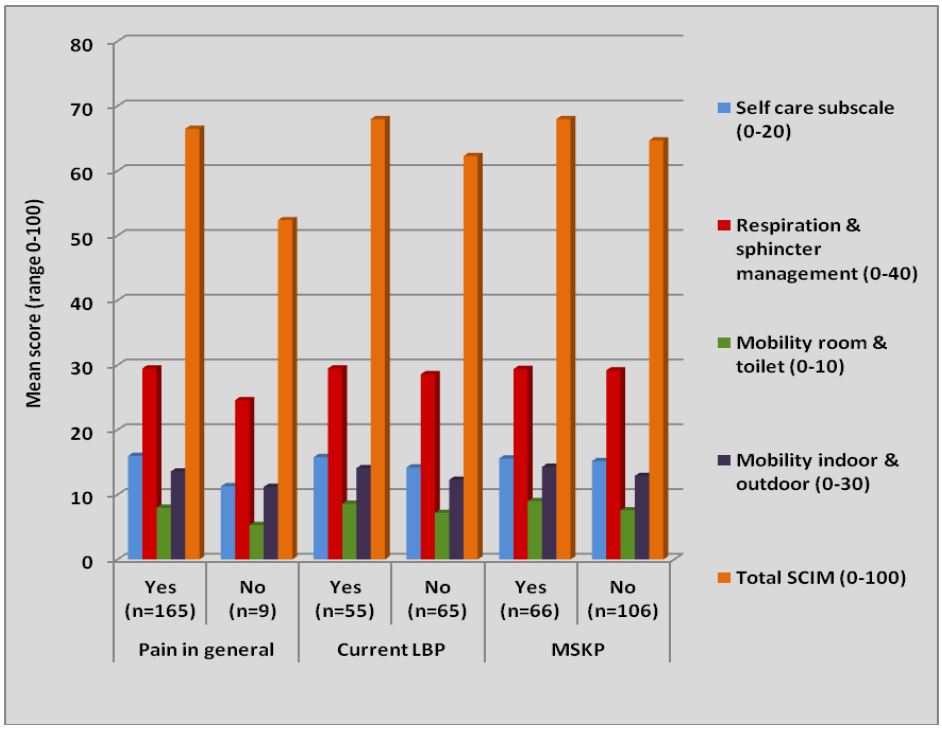

Figure 8.2.5.1: Mean SCIM scores reported by people with and without pain, LBP and MSKP
Abbreviations: SCIM, Spinal Cord Independence Measure; LBP, Low Back Pain; MSKP, Musculoskeletal Pain.

Table 8.2.5.1: Differences in function between groups with and without pain, LBP, or MSKP

	Self-care subscale	Respiration & sphincter management	Mobility room & toilet	Mobility indoors & outdoors	Total SCIM
Pain n=165	U=508.0 p=0.15 ES: r=0.10	U=487.5 p=0.86 ES: r=0.13	U=546.5 p=0.14 ES: r=0.11	U=556.5 p=0.20 ES: r=0.09	U=506.0 p=0.11 ES: r=0.11
Current LBP n=168	t=-1.39, df161 p=0.16 95%CI -3.49, 0.62 ES: d=0.12	t=-0.69, df171 p=0.48 95%CI -3.22, 1.53 ES: d=0.12	t=-2.96, df159 p=0.019[1] 95%CI -2.56, -0.24 ES: d=0.41	t=-1.19, df165 p=0.23 95%CI -4.40, 1.09 ES: d=0.16	t=-1.25, df165 p=0.26 95%CI -3.70, -11.5 ES: d=0.19
MSKP n=172	t=-0.50, df164 p=0.61 95%CI -2.04, 1.20 ES: d=0.09	t=-0.18, df169 p=0.85 95%CI -2.46, 2.05 ES d=0.02	t=-3.06, df162 p=0.003[1] 95%CI -2.20, -0.47 ES: d=0.16	t=-1.05, df170 p=0.29 95%CI -4.02, 1.22 ES: d=0.16	t=-1.06, df168 p=0.29 95%CI -9.56, 2.87 ES: d=0.16

[1]not significant post Bonferroni correction.
Abbreviations: SCIM, Spinal Cord Independence Measure; LBP, Low Back Pain; MSKP, Musculoskeletal Pain.
Statistical tests: U, Mann-Whitney U test; t, Independent t-test.

8.2.6 SCIM III; relation to number of pain/LBP days, free weeks, onset

It appeared that people who reported having pain or LBP for more days in the month reported a lower mean on the SCIM subscales and total SCIM (Appendix 8: Tables 8.10.1 and 8.10.2). However, the strength of the correlations was weak and not significant (Appendix 8: Table 8.10.3).

People who reported constant pain also reported worse function (all subscales) compared to people who were pain free most of the time (Appendix 8: Table 8.10.4). The frequency of pain or LBP-free weeks did not correlate significantly with function but the direction of the correlation indicated that the less infrequent the pain/LBP breaks, the worse the function (Table 8.2.6.1; Appendix 8: Table 8.10.5).

Table 8.2.6.1: Correlations between pain- or LBP-free weeks and function scores

	Self-care subscale	Respiration & sphincter management	Mobility room & toilet	Mobility indoors & outdoors	Total SCIM
Pain-free weeks	ρ=-0.12 p=0.13	ρ=-0.15 p=0.05	ρ=-0.10 p=0.21	ρ=0.04 p=0.59	ρ=-0.09 p=0.26
LBP-free weeks	ρ=-0.24 p≤0.01[1]	ρ=-0.13 p=0.18	ρ=-0.26 p≤0.01[1]	ρ=-0.01 p=0.88	ρ=-0.16 p=0.11

[1]not significant post Bonferroni correction; **in bold:** significant following application of the Bonferroni correction.
Abbreviations: SCIM, Spinal Cord Independence Measure; LBP, Low Back Pain.
Statistical test: ρ, Spearman's rank correlation rho.

The second hypothesis theme included examination of the relationship between onset of pain or LBP and functional independence of the participants. Therefore,

Hypothesis 0 (null): In people with iSCI there is no significant correlation between function (total SCIM or subscales) and onset of pain and LBP post iSCI.

Hypothesis 7a: In people with iSCI there is a significant correlation between function (total SCIM or subscales) and onset of pain post iSCI.

Hypothesis 7b: In people with iSCI there is a significant correlation between function (total SCIM or subscales) and onset of LBP post iSCI

Examination of the data of 154 people with pain who reported the onset of their pain following iSCI showed that, overall, the earlier the onset of pain post iSCI the slightly better their function. But relationships were small in strength and not statistically significant. The correlation in the cases of "mobility in room and toilet", "mobility indoors and outdoors" and total SCIM were slightly stronger (Tables 8.2.6.2, 8.2.6.3, 8.2.6.4). Similarly, the correlation between LBP onset post iSCI and function was negative, weak and not significant (Tables 8.2.6.2, 8.2.6.3, 8.3.6.4).

Table 8.2.6.2: Function mean scores for groups based on onset of pain post iSCI

Pain onset post iSCI	Immediately after iSCI (n=69) mean±SD, median, min-max	Within the 1st month post iSCI (n=31) mean±SD, median, min-max	Between 1-6 months post iSCI (n=25) mean±SD, median, min-max	Between 6 months & 1 year post iSCI (n=9) mean±SD, median, min-max	After 1 year post iSCI (n=20) mean±SD, median, min-max
Self-care subscale Range 0-20	15.6±4.9 18, 1-20	15.4±5.3 18, 0-20	15.5±5.5 18, 2-20	14.2±5.6 16, 4-18	12.2±7.4 15.5, 0-20
Respiration & sphincter management Range 0-40	29.6±7.3 30, 11-40	30.4±8.5 32, 0-40	29.8±7.1 30, 12-40	26.0±5.9 28, 15-33	27.1±7.1 28.5, 15-36
Mobility room & toilet Range 0-10	8.5±2.6 10, 0-10	8.3±2.9 10, 0-10	8.2±2.8 10, 0-10	6.1±3.7 8, 0-10	6.2±4.4 8.5, 0-10
Mobility indoors & outdoors Range 0-30	14.7±8.1 14, 0-30	14.9±8.5 15, 3-30	13.6±9.4 8, 3-30	8.8±6.7 7, 3-23	9.3±7.0 7, 3-25
Total SCIM Range 0-100	68.4±17.9 70, 21-100	69.1±20.8 74, 3-100	67.0±20.9 67, 26-100	55.1±18.1 63, 25-75	54.8±22.3 62.5, 18-86

Table excludes people with no pain or who did not recall the onset of their pain.
Abbreviations: SCIM, Spinal Cord Independence Measure; iSCI, incomplete Spinal Cord Injury.

Table 8.2.6.3: Function mean scores for groups based on onset of LBP post iSCI

LBP onset post SCI	Immediately after iSCI (n=39) mean±SD, median, min-max	Within the 1st month post iSCI (n=17) mean±SD, median, min-max	Between 1-6 months post iSCI (n=18) mean±SD, median, min-max	Between 6 months & 1 year post iSCI (n=8) mean±SD, median, min-max	After 1 year post iSCI (n=29) mean±SD, median, min-max
Self-care subscale Range 0-20	16.0±4.8 18, 2-20	15.1±5.4 16, 0-20	15.7±3.6 16, 6-20	16.2±3.7 18, 8-20	14.6±6.0 18, 1-20
Respiration & sphincter management Range 0-40	30.0±5.5 30, 15-40	26.8±10.3 29, 0-40	30.7±7.1 31.5, 12-40	32.2±8.1 34, 15-40	29.1±7.2 31, 15-40
Mobility room & toilet Range 0-10	8.6±2.6 10, 0-10	8.2±3.0 10, 0-10	7.9±2.4 8.5, 3-10	9.5±1.1 10, 7-10	8.0±3.3 10, 0-10
Mobility indoors & outdoors Range 0-30	15.2±7.78 15, 3-30	16.0±8.1 16, 3-30	14.2±8.8 12, 4-30	15.7±8.9 18.5, 3-28	11.6±7.7 9, 0-30
Total SCIM Range 0-100	69.8±15.4 73, 35-98	66.1±22.4 73, 3-98	68.5±17.3 66, 32-100	73.7±19.4 80.5, 33-91	63.3±20.6 68, 21-100

Table excludes people with no LBP or who did not recall the onset of their LBP.
Abbreviations: iSCI, incomplete Spinal Cord Injury; SCIM, Spinal Cord Independence Measure; LBP, Low Back Pain.

Table 8.2.6.4: Correlations between onset of pain or LBP post iSCI and function scores

	Self-care subscale	Respiration & sphincter management	Mobility room & toilet	Mobility indoors & outdoors	Total SCIM
Pain onset post iSCI n=154	ρ=-0.10 p=0.17, 95%CI -0.25, 0.05	ρ=-0.10 p=0.19, 95%CI -0.25, 0.05	ρ=-0.17 p=0.02[1] 95%CI -0.31, -0.02	ρ=-0.23 p=0.004[1] 95%CI -0.08, -0.46	ρ=-0.18 p=0.02[1] 95%CI -0.32, -0.03
LBP onset post iSCI n=111	ρ=-0.07 p=0.41, 95%CI -0.24, 0.10	ρ=0.01 p=0.83, 95%CI -0.16, 0.18	ρ=-0.09 p=0.30, 95%CI -0.20, 0.08	ρ=-0.16 p=0.08, 95%CI -0.32, 0.01	ρ=-0.08 p=0.37, 95%CI -0.25, 0.09

[1]not significant post Bonferroni correction.
Abbreviations: iSCI, incomplete Spinal Cord Injury; SCIM, Spinal Cord Independence Measure; LBP, Low Back Pain.
Statistical test: ρ, Spearman's rank correlation rho.

8.2.7 SCIM III; relation to pain extent

Analysis showed that no correlation existed between the number of areas with pain on the body and SCIM subscales or total SCIM (n=180) (Appendix 8: Table 8.11.1). This is the same finding as that found for the Greek group earlier in this chapter.

8.2.8 SCIM III; relation to quality and intensity of LBP

The third theme hypothesis examined the relationship between the quality or intensity of LBP with function. It was hypothesised that:

Hypothesis 0 (null): In people with iSCI there is no significant correlation between function (total SCIM or subscales) and the quality (sensory, affective or total PRI) of LBP.

Hypothesis 12a: In people with iSCI there is a significant correlation between function (total SCIM or subscales) and sensory PRI of LBP.

Hypothesis 12b: In people with iSCI there is a significant correlation between function (total SCIM or subscales) and affective of LBP.

Hypothesis 12c: In people with iSCI there is a significant correlation between function (total SCIM or subscales) and total PRI of LBP.

All correlations examined were weak, negative and not statistically significant (Table 8.2.8.1). Though a decrease in the quality of LBP correlated with a decrease in function these relationships were weak, thus the null hypothesis cannot be rejected. This is similar to the findings for the Greek group examined earlier.

Table 8.2.8.1: Correlations between quality of LBP (PRI) and function (SCIM)

	Self-care subscale	Respiration & sphincter management	Mobility room & toilet	Mobility indoors & outdoors	Total SCIM
S-PRI n=121	ρ=-0.10, p=0.24 r=-0.12, p=0.54 95%CI -0.29, 0.05	r=-0.09 p=0.28 95%CI -0.26, 0.08	ρ=-0.08, p=0.36 r=-0.01, p=0.90 95%CI -0.25, 0.09	ρ=-0.09, p=0.31 r=-0.7, p=0.44 95%CI -0.26, 0.08	r=-0.08 p=0.34 95%CI -0.25, 0.09
A-PRI n=121	ρ=-0.12, p=0.16 r=-0.08, p=0.33 95%CI -0.29, 0.05	r=-0.09 p=0.28 95%CI -0.26, 0.08	ρ=-0.11, p=0.21 r=-0.06, p=0.50 95%CI -0.23, 0.11	ρ=-0.02, p=0.79 r=0.009, p=0.92 95%CI -0.17, 0.17	r=-0.06 p=0.45 95%CI -0.22, 0.11
Total PRI n=118	ρ=-0.11, p=0.21 r=-0.07, p=0.44 95%CI -0.28, 0.06	r=-0.10 p=0.25 95%CI -0.27, 0.07	ρ=-0.10, p=0.27 r=-0.02, p=0.76 95%CI -0.19, 0.15	ρ=-0.07, p=0.41 r=-0.04, p=0.60 95%CI -0.21, 0.13	r=-0.08 p=0.35 95%CI -0.25, 0.09

Abbreviations: SCIM, Spinal Cord Independence Measure; PRI, Present Rating Index; S-PRI, Sensory PRI; A-PRI, Affective PRI.
Statistical test: ρ, Spearman's rank correlation rho; r, Pearson's correlation.

For the relationship between LBP intensity and function it was hypothesised that:

Hypothesis 0 (null): In people with iSCI there is no significant correlation between function (total SCIM or subscales) and intensity (on the NRS or evaluative) of LBP.

Hypothesis 13a: In people with iSCI there is a significant correlation between function (total SCIM or subscales) and intensity of current LBP.

Hypothesis 13b: In people with iSCI there is a significant correlation between function (total SCIM or subscales) and intensity of LBP over last one month.

Hypothesis 13c: In people with iSCI there is a significant correlation between function (total SCIM or subscales) and intensity of LBP over three months.

Hypothesis 13d: In people with iSCI there is a significant correlation between function (total SCIM or subscales) and evaluative PPI of LBP.

Total SCIM and most of its subscales were found to have a statistically significant negative correlation with the intensity of LBP, in particular for intensity of current LBP but none remained significant following Bonferroni correction (Table 8.2.8.2). The correlations between the evaluative dimension of LBP and function were also negative, slightly weaker and non-statistically significant (Table 8.2.8.2).

8.2.9 SCIM III; relation to QoL

Finally, the relationship between function and QoL was investigated using correlation analysis. This part of the analysis aimed to examine if reports in the literature that decreased function affects QoL (Chapter 2) could be confirmed in this particular group of participants. Analysis confirmed that when function was worse, then people classified their health as worse (Table 8.2.9.1). This correlation was strong and statistically significant. Though people also perceived their health status as worse when functional independence was reduced, this correlation was not strong enough to reach significance. Consequently, reduction of functional independence had a negative effect on health classification but not so much on health perception (Table 8.2.9.1). Overall, these results were similar to those found for the Greek group.

Table 8.2.8.2: Correlations between intensity of LBP and function (SCIM)

	Self-care subscale	Respiration & sphincter management	Mobility room & toilet	Mobility indoors & outdoors	Total SCIM
Current LBP intensity n=121	r=-0.19 p=0.02[1] 95%CI -0.35, -0.02	r=-0.23 p=0.009[1] 95%CI -0.38, -0.06	r=-0.23 p≤0.01[1] 95%CI -0.38, -0.06	r=-0.13 p=0.13 95%CI -0.30, 0.04	r=-0.23 p=0.008[1] 95%CI -0.38, -0.06
LBP intensity over last 1 month n=119	r=-0.13 p=0.013[1] 95%CI -0.03, -0.09	r=-0.19 p=0.03[1] 95%CI -0.30, -0.02	r=-0.17 p=0.051 95%CI -0.33, 0.00	r=-0.07 p=0.43 95%CI -0.24, 0.10	r=-0.17 p=0.051 95%CI -0.33, 0.00
LBP intensity last 3 months n=118	r=-0.05 p=0.54 95%CI -0.22, 0.12	r=-0.12 p=0.18 95%CI -0.29, 0.05	r=-0.06 p=0.49 95%CI -0.23, 0.11	r=-0.02 p=0.79 95%CI -0.19, 0.15	r=-0.06 p=0.49 95%CI -0.23, 0.11
Evaluative PPI n=111	ρ=-0.10, p=0.24 r=-0.12,p=0.54 95%CI -0.29, 0.05	r=-0.27 p=0.12 95%CI -0.42, -0.10	ρ=-0.10, p=0.24 r=-0.12, p=0.54 95%CI -0.29, 0.05	ρ=-0.10, p=0.24 r=-0.12,p=0.54 95%CI -0.29, 0.05	r=-0.12 p=0.54 95%CI -0.29, 0.05

[1]not significant post Bonferroni correction.
Abbreviations: SCIM, Spinal Cord Independence Measure; LBP, Low Back Pain; PPI, Present Pain Intensity.
Statistical tests: ρ, Spearman's rank correlation rho; r, Pearson's correlation.

Table 8.2.9.1: Correlation between function and QoL

	Self-care subscale	Respiration & sphincter management	Mobility room & toilet	Mobility indoors & outdoors	Total SCIM
EQ-5D Index n=156	r=0.47, **p≤0.001*** **	r=0.37 **p≤0.001*** **	r=0.40, **p≤0.001*** **	r=0.31, **p≤0.001*** **	r=0.41 **p≤0.001*** **
EQ VAS n=156	ρ=0.07, p=0.33 r=-0.02, p=0.78	r=0.03 p=0.66	ρ=0.02, p=0.77 r=-0.06, p=0.41	ρ=-0.11, p=0.12 r=-0.002, p=0.97	ρ=0.009 p=0.90

***Significant at p≤0.001 level, **in bold:** significant following application of the Bonferroni correction.
Abbreviations: SCIM, Spinal Cord Independence Measure; EQ-5D, Quality of Life, EQ-VAS, Quality of Life Visual Analogue Scale.
Statistical tests: ρ, Spearman's rank correlation rho; r, Pearson's correlation.

8.3 Conclusion

This chapter confirmed the unidimensionality of the subscales of both GR-SCIM III and SCIM III. Internal consistency for the two versions was almost equal and criterion/concurrent validity accepted. Ceiling effects were noticed for both SCIM III versions.

When the demographic profile characteristics were examined for the Greek group, age seemed to have a negative impact on function. For the rest of the group the type of injury seemed to affect function. The presence of any pain category examined did not affect function significantly either for the Greek or the rest of the group. Worse LBP quality correlated with worse function for both groups but the correlations were not very strong. The correlation was stronger in the case of increased intensity of LBP for both groups but still not statistically significant. Finally, overall reduction of functional independence related to a significantly lower health classification but not significantly lower perception of health status.

The next chapter is the final chapter to examine results of the data analysis conducted in this survey. It will examine the hypotheses themes discussed in the three previous chapters of analysis and will compare the groups within and between nations. Thus, the next chapter will deal with the cross-national analysis of the data.

Chapter 9; Results: Cross-national analysis

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There is no such thing as a little country. The greatness of people is no more determined by their numbers than the greatness of a man is by his height.
Victor Hugo (1802 – 1885) - French Writer

Part 1; Participants' demographic characteristics and pain presence across the countries

9.1.1 Introduction

The previous three chapters of the results described in detail the profiles of the total group of people participating in the current survey. They explored the experience of pain and investigated how it related to function and QoL.

This chapter will examine the same relationships and seek to answer the same questions, however, this time within and between the three participating countries and will investigate the effect of the country of residence on the main variables under investigation. The aim is to analyse similarities and differences between the groups from the three participating countries which will answer the objective of the study related to the cross-national analysis. The importance and contribution to knowledge of cross-national research was explored in detail in Chapter 2.

The format of the chapter will be similar to the previous chapters starting by presenting the demographic profiles of people from each nation followed by exploring their experience of pain. Then QoL and function will be investigated. The statistical tests used tend to be non-parametric, in particular, for the UK and Greek groups where the group sizes are often smaller than 50 people in each sub-group.

9.1.2 Bonferroni correction

In the current part of the analysis the number of multiple tests done on the variables of interest were either six or seven thus, the α-level of statistical significance set by Bonferroni was $p \leq 0.008$ or $p \leq 0.007$ depending on the variable examined (Appendix 9: Table 9.a.1.1).

9.1.3 Across nations; general results

In total there were 122 people from the USA, 52 from the UK and 45 from Greece. There were some significant differences noticed in the profile and injury characteristics of people from the three participating countries. These are presented below.

A significant difference in the mean age of people from the three participating countries was found ($p \leq 0.001$, $H=34$, Kruskall-Wallis H test, $n=217$). Further two-group analysis showed that Greeks were significantly older than those from the USA ($p<0.001$, $U=1106.5$, Mann-Whitney U test) and the UK ($p \leq 0.001$, $U=608$, Mann-Whitney U test). In addition, people from the UK were significantly older than those from the USA ($p=0.009$, $U=2153$, Mann-Whitney U test) (Appendix 9, Table 9.a.2.1). Similarly, a significant age difference at the time of the injury was found between people from the three participating countries ($p \leq 0.001$, $F=20.15$, one-way ANOVA). The Greek group was significantly older at the time of the injury than both the UK ($p \leq 0.001$, I-J=-13.9, Bonferroni post hoc) and the USA groups ($p \leq 0.001$, I-J=-13.9, Bonferroni post hoc) (Appendix 9, Table 9.a.2.1).

Another difference between people across countries was the cause of injury ($p \leq 0.001$, $x^2=26.08$, extended chi-square). Two-group analysis showed that significantly more Greeks had a non-traumatic cause of injury compared to people from the UK ($p \leq 0.001$, $\chi^2=16.9$, Pearson's chi-square) and USA ($p \leq 0.001$, $\chi^2=21.5$, Pearson's chi-square) (Appendix 9, Table 9.a.2.2). Finally, some differences were found in the level of education and the marital status of participants. People with the highest level of education (above high school) were from the UK and their education level was significantly higher than those from the USA ($p=0.006$, $\chi^2=7.43$, Pearson's chi-square) (Appendix 9, Table 9.a.2.2). Tables in Appendix 9, 9.a.2.1-9.a.2.6 include all examined demographic profile characteristics between people from the three countries.

9.1.4 Across nations; pain, MSKP and LBP

People from Greece reported the lowest cases of pain presence among all participants. Indeed, there was a significant difference in the pain presence between the three countries (χ^2=13.282, df2, p≤0.001, extended chi-square). Two-group comparisons confirmed that Greeks reported significantly less cases of pain presence than people from the USA (p=0.04, Fishers exact) and the UK (p=0.006, χ^2=7.514, chi-square) (Tables 9.1.1 and 9.1.2). Differences in reported back pain between people from the three countries were not significant. The presence of MSKP did not differ between people from the three countries and it was only within the USA that there was a significant difference between those with and without MSKP (Tables 9.1.1 and 9.1.2)

Table 9.1.1: Prevalence of pain categories per national group

Category of pain	Pain prevalence % (among all participants)			Pain prevalence % (among people with pain only)		
	USA	**UK**	**GR**	**USA**	**UK**	**GR**
Pain in general	94.3 n=122 95% CI 88%, 97%	96.2 n=52 95% CI 87%, 98%	77.8 n=45 95% CI 63%, 87%	n/a	n/a	n/a
Musculoske-letal pain	36.7 n=120 95% CI 28%, 45%	42.3 n=52 95% CI 30%, 56%	37.8 n=42 95% CI 27%, 55%	38.9 n=113	44 n=50	53.1 n=32
Back pain	72.1 n=120 95% CI 69%, 84%	75 n=52 95% CI 63%, 86%	76.2 n=42 95% CI 61%, 86%	77.9 n=113	78 n=50	100 n=32
LBP life prevalence	73 n=122 95% CI 64%, 80%	75 n=52 95% CI 80%, 97%	73.3 n=45 95% CI 58%, 84%	77.4 n=115	78 n=50	94.3 n=35
LBP point prevalence	65.8 n=117 95% CI 57%, 74%	70.6 n=51 95% CI 57%, 81%	69.8 n=43 95% CI 54%, 81%	70 n=110	73.5 n=79	90.9 n=33
LBP over the last 1 month prevalence	65.3 n=118 95% CI 56%, 73%	72.5 n=51 95% CI 59%, 82%	72.1 n=43 95% CI 57%, 83%	69.4 n=111	75.5 n=49	93.9 n=33
LBP over the last 3 months prevalence	68.4 n=117 95% CI 58%, 75%	72.5 n=51 95% CI 59%, 82%	72.1 n=43 95% CI 57%, 83%	72.7 n=110	75.5 n=49	93.9 n=33

Abbreviations: MSKP, Musculoskeletal Pain; LBP, Low Back Pain.

In Chapter 6, Section 6.1.5, it was found that a high proportion of people reported LBP (all time periods) (hypothesis 1). Here these findings are examined across the nations.

Hypothesis 0 (null): In people with iSCI there is no significant difference in the percentage of those with LBP and those without for each national group.

Hypothesis 1: In people with iSCI there is a significant difference in the percentage of those with LBP and those without for each national group.

For each individual country the same result as for the total group of participants was found; more people reported having LBP than not having LBP at all time periods. All results were statistically significant for the USA group following application of the Bonferroni correction. Though not many findings passed the Bonferroni correction for the other two countries the effect sizes were strong, thus, the practical significance must be considered (Table 9.1.2).

9.1.5 Across nations; relationship between LBP and MSKP

In Chapter 6, Section 6.1.6, it was found that when LBP prevalence (all time periods) increased so did MSKP prevalence. This correlation is examined across the countries. Therefore the added hypothesis in the study is:

Hypothesis 0 (null): In people with iSCI there is no significant correlation between LBP and MSKP for each national group.

Hypothesis new: In people with iSCI there is a significant correlation between LBP and MSKP for each national group.

Using Phi test (ϕ) for correlation, the original finding of the positive correlation between LBP and MSKP presence was supported within each individual country group. The strength of the correlations was moderate, but for people from the UK it was stronger and passed the Bonferroni α-level of significance (Table 9.1.3).

Table 9.1.2: Differences in pain presence within and between national groups

Category of pain	Within countries Statistical Test			Between countries Statistical Test
	USA	**UK**	**GR**	
Pain in general	χ^2=95.6, df1 **p≤0.001*** ** ϕ=0.88, n=122	χ^2=44.3, df1 **p≤0.001*** ** ϕ=0.92, n=52	χ^2=13.8, df1 **p≤0.001*** ** ϕ=0.55, n=45	χ^2=13.2, df2 **p≤0.001*** ** People from Greece reported less pain presence than people from USA (**p=0.04**) and UK (**p=0.006**)
Back pain	χ^2=36.3, df1 **p≤0.001*** ** ϕ=0.54, n=120	χ^2=15.0, df1 **p≤0.001*** ** ϕ=0.53, n=52	χ^2=11.5, df1 p≤0.01[1] ϕ=0.50, n=42	χ^2=0.03, df2 p=0.98
Musculoskeletal pain	χ^2=8.5, df1 **p=0.003** ** ϕ=0.26, n=120	χ^2=0.9, df1 p=0.32 ϕ=0.13, n=52	χ^2=1.5, df1 p=0.21 ϕ=0.18, n=42	χ^2=0.68, df2 p=0.71
LBP life prevalence	χ^2=25.7, df1 **p≤0.001*** ** ϕ=0.45, n=122	χ^2=13.0, df1 **p≤0.001*** ** ϕ=0.50, n=52	χ^2=9.8, df1 p=0.02[1] ϕ=0.46, n=42	χ^2=0.08, df2 p=0.96
LBP point prevalence	χ^2=12.4, df1 **p≤0.001*** ** ϕ=0.31, n=117	χ^2=8.6, df1 p=0.03[1] ϕ=0.40, n=51	$\chi^2$6.72=, df1 p≤0.01[1] ϕ=0.39, n=43	χ^2=0.35, df2 p=0.83
LBP over the last 1 month prevalence	χ^2=10.9, df1 **p≤0.001*** ** ϕ=0.29, 118	χ^2=10.3, df1 p=0.01[1] ϕ=0.44, n=51	χ^2=8.3, df1 p=0.04[1] ϕ=0.42, n=43	χ^2=1.21, df2 p=0.54
LBP over the last 3 months prevalence	χ^2=14.6, df1 **p≤0.001*** ** ϕ=0.34, n=117	χ^2=10.3, df1 **p≤0.001*** ** ϕ=0.44, n=51	χ^2=8.3, df1 **p=0.004** ** ϕ=0.42, n=43	χ^2=0.50, df2 p=0.77

[1]not significant post Bonferroni correction; ***Significant at p≤0.001 level, **in bold:** significant following application of the Bonferroni correction or Bonferroni post hoc; [1]not significant post Bonferroni correction

Abbreviations: MSKP, Musculoskeletal Pain; LBP, Low Back Pain

Statistical tests: χ^2, Goodness of fit Chi square or extended chi-square; ϕ, Phi test for effect size

Table 9.1.3: Correlation between LBP and MSKP presence across the national groups

	USA	UK	Greece
LBP lifetime with MSKP	ϕ=0.23 p≤0.01[1], n=120 95%CI 0.08, 0.37	ϕ=0.50 **p≤0.001*** ** n=51 95%CI 0.37, 0.60	ϕ=0.38 p≤0.01[1], n=42 95%CI 0.18, 0.55
LBP current with MSKP	ϕ=0.23 p=0.02[1], n=116 95%CI 0.07, 0.37	ϕ=0.55 **p≤0.001*** ** n=50 95%CI 0.43, 0.64	ϕ=0.33 p=0.04[1], n=41 95%CI 0.08, 0.52
LBP over last 1 month with MSKP	ϕ=0.22 p≤0.01[1], n=118 95%CI 0.06, 0.37	ϕ=0.44 **p=0.002** ** n=50 95%CI 0.28, 0.58	ϕ=0.38 p≤0.01[1], n=42 95%CI 0.19, 0.55
LBP over last 3 months with MSKP	ϕ=0.18 p=0.058 n=115 95%CI 0.01, 0.34	ϕ=0.44 **p=0.002** ** n=50 95%CI 0.28, 0.58	ϕ=0.38 p≤0.01[1] n=42 95%CI 0.15, 0.57

[1]not significant post Bonferroni correction; **Significant at p≤0.01 level, ***Significant at p≤0.001 level, **in bold:** significant following application of the Bonferroni correction; [1]not significant post Bonferroni correction;
Abbreviations: MSKP, Musculoskeletal Pain; LBP, Low Back Pain.
Statistical test: ϕ, Phi test.

9.1.6 Pain, MSKP and LBP across nations; relation to demographic profile characteristics

Earlier, in Chapter 6, using the pooled group only two significant differences were found for the categories of pain under examination in combination with the demographic profile characteristics of the participants; 1) people with paraplegia reported significantly more cases of LBP presence (all time periods) than people with tetraplegia, and 2) people with non-traumatic injury reported significantly more cases of current LBP than those with a traumatic injury (Chapter 6, Section 6.1.7). In addition, earlier in this chapter some differences in the demographic profile characteristics of people from the three countries were found (Section 9.1.3).

9.1.6.1 Gender across nations

The interaction effect of gender and country of residence on each category of pain[34] was examined but in no case was this effect statistically significant (Table 9.1.4).

[34] For an explanation on the interaction effect methods see Chapter 5, Section 5.16

Examining each group of the three participating countries no significant differences were found in the presence of pain or MSKP between males and females when the chi-square or Fisher exact tests were applied (Table 9.1.5; Appendix 9: Table 9.a.3.1). The proportion of pain presence for some groups, however, seemed to be rather different and they were examined further in two-group analysis. This revealed that males from Greece reported pain significantly less often than males from both the USA ($p \leq 0.01$, Fisher's exact, n=104) and the UK ($p \leq 0.01$, Fisher's exact, n=53). This was not found within the female groups (Appendix 9: Table 9.a.3.4). Women within all groups of the three countries reported more cases of LBP presence (all time periods) than males, but these differences did not reach significant levels (Table 9.1.5), which was similar to the pooled data examined in Chapter 6.

9.1.6.2 Cause of injury across nations

The interaction effect of cause of injury and country of residence did not have a statistically significant impact (therefore could not efficiently predict) the presence of any of the pain categories examined with one exception that of pain in general ($p=0.007$, $\chi^2=9.5$, Likelihood ratio Chi-square, n=219). However, exactly what the effect was could not be identified as none of the individual estimates (two-group comparisons between the variables) were found to be significant. Possibly, larger group sizes were needed to identify the specific effects (Table 9.1.4).

Within each national group people with a non-traumatic injury reported the presence of the pain categories examined more often than people with a traumatic injury. People from the USA with a non-traumatic injury reported a higher proportion of pain presence than those from the other two countries (Appendix 9: Table 9.a.3.2). No differences passed the Bonferroni alpha level of significance (Table 9.1.5). Two-group comparisons were conducted between those groups whose proportion of pain reports seemed to differ a lot and it was found that Greeks with either traumatic or non-traumatic cause of injury reported significantly less proportion of pain presence than

people with traumatic or non-traumatic (respectively) injuries from both the USA and UK (Appendix 9: Table 9.a.3.5).

9.1.6.3 Level of injury across nations

Logistic regression analysis showed that the interaction effect between the level of injury and the country of residence was significant on some of the pain categories examined (Table 9.1.4). On two occasions (the effect on lifetime LBP and LBP over the last month) the significance did not pass the Bonferroni α-level thus it cannot be accepted here, but could be considered in future studies. The interaction between the level of injury and country of residence could possibly predict the presence of pain in general as the effect was statistically significant ($p \leq 0.001$, $\chi^2=23.82$, Likelihood ratio, n=217) but it could not be identified exactly where the effect was as the individual estimates were not found to be significant. Finally, the interaction effect between level of injury and country of residence significantly affected the presence of LBP over the last three months ($p=0.005$, $\chi^2=16.53$, likelihood chi-square, n=207). Further analysis showed that people with tetraplegia from both the USA and the UK were less likely to report pain; interaction effect of USA and tetraplegia on pain presence: p=0.04, (b=-1.07, OR=0.34); interaction effect of UK and tetraplegia on pain presence: p=0.04, (b=-1.24, OR=0.28) (Table 9.1.4).

Looking at the level of injury for each individual group from the three countries, people with paraplegia reported a higher proportion of all categories of pain examined (Appendix 9: Table 9.a.3.3). However, these differences were not significant with the exception of the USA group for the presence of lifetime LBP ($p=0.006$, $x^2=7.4$, chi-square test). Two-group comparisons were conducted among groups which seemed to differ in their reported percentages and showed that Greeks with paraplegia reported pain in general significantly less often than people with paraplegia from the USA ($p \leq 0.001$, Fisher's exact, n=88) and the UK groups ($p=0.024$, Fisher's exact, n=58) (Appendix 9: Table 9.a.3.6). The level of injury was divided in cervical, thoracic, and lumbar, as in earlier analysis, and the related analysis is presented at Appendix 9, Tables 9.a.3.7, 9.a.3.8. No other significant differences were found when the level of injury was examined within or between the groups of people from the three countries.

Table 9.1.4: Interaction effects between country of residence and demographic/injury characteristics on the presence of the pain categories

	Pain in general	LBP lifetime	LBP current	LBP last 1 month	LBP last 3 months	MSKP
Gender (Male – Female)	p=0.09 R^2=0.10, n=215 χ^2=9.50, df5	p=0.38 R^2=0.03, n=215 χ^2=5.22, df5	p=0.54 R^2=0.02, n=206 χ^2=4.03, df5	p=0.23 R^2=0.04, n=208 χ^2=6.81, df5	p=0.26 R^2=0.04, n=205 χ^2=6.41, df5	p=0.26 R^2=0.04, n=209 χ^2=6.43, df5
Cause of injury (Traumatic - Non-traumatic)	**p=0.007**¹ R^2=0.15, n=219 χ^2=15.9, df5	p=0.17 R^2=0.05, n=219 χ^2=7.60, df5	p=0.26 R^2=0.04, n=210 χ^2=6.40, df5	p=0.22 R^2=0.04, n=212 χ^2=6.93, df5	p=0.22 R^2=0.04, n=209 χ^2=6.89, df5	p=0.16 R^2=0.04, n=213 χ^2=7.28, df5
Level of injury (tetraplegia – paraplegia)	**p≤0.001***¹ R^2=0.23, n=217 χ^2=23.82, df5	p=0.01² R^2=0.09, n=217 χ^2=14.26, df5	p=0.06 R^2=0.06, n=208 χ^2=10.32, df5	p=0.02² R^2=0.08, n=210 χ^2=12.84, df5	**p=0.005** R^2=0.10, n=207 χ^2=16.53, df5 USA*Tetraplegia: p=0.04*, df1, b=-1.07, SE=0.52, Wald=4.16, OR=0.34 95% CI for OR 0.12, 0.95 UK*Tetraplegia: p=0.04, df1, b=-1.24, SE=0.63, Wald=3.88, OR=0.28, 95% CI for OR 0.08, 0.9	p=0.38 R^2=0.03, n=211 χ^2=5.30, df5
Age	p=0.01² R^2=0.11, n=210 χ^2=10.73, df3	p=0.90 R^2=0.004, n=219 χ^2=0.56, df3	p=0.93 R^2=0.003, n=219 χ^2=0.42, df3	p=0.73 R^2=0.009, n=203 χ^2=1.29, df3	p=0.79 R^2=0.007, n=219 χ^2=1.03, df3	p=0.88 R^2=0.004, n=204 χ^2=0.65, df3
Time since injury	p=0.09 R^2=0.10, n=215 χ^2=9.50, df5	p=0.98 R^2=0.001, n=218 χ^2=0.14, df3	p=0.93 R^2=0.003, n=209 χ^2=0.43, df3	p=0.81 R^2=0.006, n=211 χ^2=0.94, df3	p=0.44 R^2=0.01, n=208 χ^2=2.66, df3	p=0.50 R^2=0.01, n=212 χ^2=2.32, df3

Significant at p≤0.01 level, ***Significant at p≤0.001 level, **in bold: significant following application of the Bonferroni correction; ¹Significant but analysis could not identify what the exact effect was; ²not significant post Bonferroni correction, Abbreviations: MSKP, Musculoskeletal Pain; LBP, Low Back Pain; SE, Standard Error; OR, Odd Ratio; *Statistical tests*: χ^2, Likelihood ration Chi-square; Wald test chi-square distribution; R^2, Nagelkerke R square (pseudo-R).

Table 9.1.5: Summary results of statistical differences in pain presence within each national group divided by demographic profile characteristics

		Total groups of respondents			Groups include people with pain only		
		USA	**UK**	**GR**	**USA**	**UK**	**GR**
Sex (Male – Female)	Pain in general	χ^2=0.08, p=0.77	χ^2=0.05, p=0.82	χ^2=1.44, p=0.23	n/a	n/a	n/a
	Back pain	χ^2=0.13, p=0.71	χ^2=0.51, p=0.47	χ^2=1.59, p=0.20	χ^2=0.08, p=0.77	χ^2=0.73, p=0.39	constant
	MSKP	χ^2=2.23, p=0.13	χ^2=0.92, p=0.33	χ^2=2.33, p=0.12	χ^2=2.18, p=0.14	χ^2=1.03, p=0.31	χ^2=1.2, p=0.27
	LBP lifetime	χ^2=0.81, p=0.36	χ^2=0.94, p=0.31	χ^2=3.06, p=0.08	χ^2=0.73, p=0.39	χ^2=1.25, p=0.26	χ^2=2.0, p=0.15
	LBP current	χ^2=0.17, p=0.68	χ^2=0.83, p=0.36	Fisher's, p=0.28	χ^2=0.12, p=0.72	χ^2=1.05, p=0.30	Fisher's, p=1.0
	LBP 1 month	χ^2=0.24, p=0.61	χ^2=1.66, p=0.19	Fisher's, p=0.14	χ^2=0.2, p=0.65	χ^2=2.06, p=0.15	Fisher's, p=0.48
	LBP 3 months	χ^2=0.52, p=0.46	χ^2=1.66, p=0.19	Fisher's, p=0.14	χ^2=0.50, p=0.74	χ^2=0.20, p=0.15	Fisher's, p=0.48
Cause of injury (Traumatic - Non traumatic)	Pain in general	Fisher's, p=0.34	Fisher's, p=0.10	Fisher's, p=0.48	n/a	n/a	n/a
	Back pain	χ^2=4.5, p=0.03[1]	Fisher's, p=0.67	Fisher's, p=0.45	Fisher's, p=0.15	Fisher's, p=0.39	constant
	MSKP	χ^2=5.35, p=0.02[1]	Fisher's, p=1.0	χ^2=1.84, p=0.17	χ^2=4.1,p=0.04[1]	Fisher's, p=1.0	Fisher's, p=0.45
	LBP lifetime	χ^2=4.46, p=0.03[1]	Fisher's, p=0.69	Fisher's, p=0.17	χ^2=2.66, p=0.10	Fisher's, p=0.67	Fisher's, p=0.13
	LBP current	χ^2=3.83, p=0.05[1]	Fisher's, p=1.0	Fisher's, p=0.17	χ^2=2.24, p=0.13	Fisher's, p=1.0	Fisher's, p=0.25
	LBP 1 month	χ^2=2.4, p=0.12	Fisher's, p=1.0	Fisher's, p=0.09	χ^2=1.18, p=0.27	Fisher's, p=0.69	Fisher's, p=0.1 χ^2=4.2,p=0.03[1]
	LBP 3 months	χ^2=2.7, p=0.09	Fisher's, p=1.0	Fisher's, p=0.09	χ^2=1.38, p=0.24	Fisher's, p=0.69	Fisher's, p=1.0 χ^2=4.2,p=0.03[1]
Level of injury (tetraplegia – paraplegia)	Pain in general	Fisher's, p=0.01[1]	Fisher's, p=0.20	Fisher's, p=0.71	n/a	n/a	n/a
	Back pain	χ^2=6.5, p=0.01[1]	χ^2=5.2,p=0.02[1]	Fisher's, p=0.69	χ^2=2.3, p=0.12	Fisher's, p=0.08	constant
	MSKP	χ^2=2.41, p=0.12	χ^2=1.47, p=0.22	χ^2=0.25, p=0.61	χ^2=1.17, p=0.27	χ^2=0.93, p=0.33	Fisher's, p=0.44
	LBP lifetime	χ^2=7.4,**p=0.006****	χ^2=3.7,p=0.054	Fisher's, p=0.17	χ^2=3.36, p=0.06	Fisher's, p=0.17	Fisher's, p=0.09 χ^2=4.62,p=0.03[1]
	LBP current	χ^2=5.74,p=0.01[1]	χ^2=1.9, p=0.16	Fisher's, p=0.29	χ^2=1.5, p=0.11	χ^2=0.87, p=0.35	Fisher's, p=0.21
	LBP 1 month	χ^2=2.97, p=0.08	χ^2=5.4,p=0.02[1]	Fisher's, p=0.16	χ^2=0.78, p=0.37	χ^2=3.6,p=0.055	Fisher's, p=0.08 χ^2=4.8,p=0.02[1]
	LBP 3 months	χ^2=6.48,p=0.01[1]	χ^2=5.4,p=0.02[1]	Fisher's, p=0.16	χ^2=2.93, p=0.08	χ^2=3.6,p=0.055	Fisher's, p=0.08 χ^2=4.8,p=0.02[1]

[1]not significant post Bonferroni correction; **Significant at p≤0.01 level; **in bold:** significant following application of the Bonferroni correction. Abbreviations: MSKP, Musculoskeletal Pain; LBP, Low Back Pain. *Statistical tests*: χ^2, Pearson's chi-square; Fisher's exact.

Table 9.1.6: Summary results of statistical differences in pain presence within each national group divided by age and time since injury

		Groups include total number of respondent			Groups exclude people without pain in general		
		USA	UK	GR	USA	UK	GR
Age	Pain in general	t=-0.92, p=0.35, 95% CI -12.2, 4.43	t=0.36, p=0.71, 95% CI -15.5, 22.4	t=-0.49, p=0.62, 95% CI -15.8, 9.6	n/a	n/a	n/a
	Back pain	t=0.57, p=0.56, 95% CI -3.3, 6.16	t=0.99, p=0.32, 95% CI -4.65, 13.8	t=-1.57, p=0.12, 95% CI -18.7, 2.35	t=1.16, p=0.24, 95% CI -2.22, 8.59	t=0.92, p=0.36, 95% CI -5.5, 4.86	t=-1.57, p=0.12, 95% CI -18.7, 2.35
	MSKP	t=-0.51, p=0.61, 95% CI -5.23, 3.08	t=3.05, **p=0.004**** 95% CI 3.5, 16.98	t=-2.24, p=0.03[1] 95% CI -18.8, 0.99	t=-0.32 p=0.74, 95% CI -4.96, 3.55	t=3.03, p=0.04[1] 95% CI 3.49,17.27	t=-1.71, p=0.09, 95% CI -18.5, 1.62
	LBP lifetime	t=0.39, p=0.69, 95% CI -3.56, 5.32	t=1.26, p=0.21, 95% CI -3.3, 14.42	t=-1.16, p=0.25, 95% CI -17.9, 4.84	t=0.39, p=0.69, 95% CI -3.56, 5.32	t=1.26, p=0.21, 95% CI -3.3, 14.42	t=-0.91, p=0.36, 95% CI -17.2, 6.45
	LBP current	t=-0.37, p=0.71, 95% CI -5.09, 3.47	t=1.43, p=0.15, 95% CI -2.41, 14.4	t=-1.28, p=0.20, 95% CI -17.0, 3.77	t=-0.03, p=0.97, 95% CI -4.96, 4.52	t=1.38, p=0.17, 95% CI -2.8, 15.29	t=-0.64, p=0.52, 95% CI -25.4, 13.2
	LBP 1 month	t=-0.49, p=0.62, 95% CI -5.35, 3.22	t=1.34, p=0.18, 95% CI -2.88, 14.5	t=-2.05, p=0.04[1] 95% CI -19.9, -0.1	t=-0.15, p=0.88, 95% CI -4.96, 4.26	t=1.28, p=0.20, 95% CI -3.39, 15.4	t=-1.75, p=0.09, 95% CI -38.5, 2.94
	LBP 3 months	t=0.18, p=0.85, 95% CI -3.94, 4.75	t=1.34, p=0.18, 95% CI -2.88, 14.5	t=-2.05, p=0.04[1] 95% CI -19.9, -0.1	t=0.59, p=0.55, 95% CI -3.29, 6.11	t=1.28, p=0.20, 95% CI -3.39, 15.4	t=-1.75, p=0.09, 95% CI -35.8, 2.94
Time since injury	Pain in general	t=-0.66, p=0.5, 95% CI -10.2, 5.11	t=1.40, p=0.16, 95% CI -5.09, 28.9	t=-0.97, p=0.33, 95% CI -8.6, 3.0	n/a	n/a	n/a
	Back pain	t=-0.10, p=0.10, 95% CI -4.41, 3.96	t=0.08, p=0.93, 95% CI -7.6, 8.24	t=-0.32, p=0.74, 95% CI -7.6, 5.48	t=0.46, p=0.64, 95% CI -3.7, 6.01	t=-0.45, p=0.65, 95% CI -10.4, 6.58	n/a as no BP replies were n=0
	MSKP	t=-1.22, p=0.22, 95% CI -5.65, 1.34	t=0.30, p=0.76, 95% CI -5.76, 7.81	t=-2.2, p=0.03[1] 95% CI -9.9, -0.53	t=-1.29, p=0.19, 95% CI -5.88, 1.24	t=0.06, p=0.94, 95% CI -6.69, 7.14	t=-1.79, p=0.08, 95% CI -11.6, 0.79
	LBP lifetime	t=-0.12, p=0.9, 95% CI -4.12, 3.63	t=-0.06, p=0.94, 95% CI -7.97, 7.44	t=0.75, p=0.45, 95% CI -3.24, 7.11	t=-0.21, p=0.83, 95% CI -4.71, 3.79	t=-0.58, p=0.56, 95% CI -10.5, 5.81	t=3.37, p=0.02[1] 95% CI -6.99, 28.3
	LBP current	t=0.11, p=0.90, 95% CI -3.55, 4.01	t=-0.04, p=0.96, 95% CI -7.63, 7.3	t=0.10, p=0.91, 95% CI -5.24, 5.8	t=0.08, p=0.93, 95% CI -3.9, 4.23	t=-0.49, p=0.62, 95% CI -9.79, 5.92	t=1.72, p=0.09 95% CI -1.67, 19.7
	LBP 1 month	t=-0.19, p=0.84 95% CI -4.11, 3.37	t=-0.32, p=0.74 95% CI -8.85, 6.37	t=0.37, p=0.70, 95% CI -4.61, 6.74	t=-0.26, p=0.79, 95% CI -4.54, 3.48	t=-0.82, p=0.41, 95% CI -11.3, -4.7	t=2.83, **p=0.008**** 95% CI -4.73, 28.8
	LBP 3 months	t=1.43, p=0.15, 95% CI -1.12, 6.69	t=-0.32, p=0.74, 95% CI -8.85, 6.73	t=0.37, p=0.70, 95% CI -4.61, 6.74	t=1.54, p=0.12, 95% CI -0.96, 7.77	t=-0.82, p=0.41, 95% CI -11.3, 4.74	t=2.83, **p=0.008**** 95% CI -4.73, 28.8

[1]not significant post Bonferroni correction; **Significant at p≤0.01 level, **in bold:** significant following application of the Bonferroni correction; Abbreviations: MSKP, Musculoskeletal Pain; LBP, Low Back Pain. *Statistical test:* t, Independent t-test.

9.1.6.4 Age across nations

For the pooled data examined in Chapter 6, age did not differ significantly between people with and without the pain categories tested. The interaction between the country of residence and age did not have a significant effect on any of the pain categories examined. This means that the presence of pain (all types) could not be predicted by age in combination with where they lived (Table 9.1.4). Examining the groups of the three countries separately the finding that age did not differ, in general, between people with and without the pain categories was maintained. However, within the UK group, people without MSKP were significantly older than those with MSKP ($p \leq 0.004$, $t=3.05$, 95% CI 3.5, 16.98, independent t-test, $n=114$) (Table 9.1.6; Appendix 9: Table 9.a.3.9). It has already been established that the Greeks were significantly older than people from the USA and the UK (Section 9.1.3). For this reason, two-group comparisons were conducted to investigate if age differed among people from different nations with and without pain. It was found that the Greeks with any type of pain were significantly older than those with any type of pain from both the USA and the UK, which was not found among people without pain (Table 9.1.7). Earlier analysis had shown that people from the UK were significantly older than those from the USA. Two-group comparisons between them did not reveal any age differences in people with pain and in people without pain (all categories) (Table 9.1.7). These results show the impact of age on the presence of the pain categories is greater at later age stages.

Table 9.1.7: Differences in mean age of people across national groups

		Yes (pain category)	No (pain category)
		Greece	
USA	Pain in general	t=-6.69,df142, n=150, **p≤0.001*** ** 95% CI -21.7, -11.8	t=-2.8, df46, n= 17, p=0.06[1] 95% CI -20.2, -3.54
	Back pain	t=-7.9, df118, n=125, **p≤0.001*** ** 95% CI -24.9, -14.9	t=-2.6, df34, n=37, p≤0.01[1] 95% CI 22.5, -2.7
	MSKP	t=-7.34, df57, n=61, **p≤0.001*** ** 95% CI -31.7, -18.1	t=-4.7, df95, n=145, **p≤0.001*** ** 95% CI -19.2, -7.9
	LBP lifetime	t=-6.7,df115, n=122, **p≤0.001*** ** 95% CI -23.3, -12.7	t=-2.7, df42, n=145, p≤0.01[1] 95% CI -20.4, -2.9
	LBP current	t=-6.9, df101, n=107, **p≤0.001*** ** 95% CI -24.4, -13.6	t=-3.6, df49, n=52, **p≤0.001*** ** 95% CI -22.6, -6.4
	LBP last 1 month	t=-7.23,df103, n=104, **p≤0.001*** ** 95% CI -24.7, -14.1	t=-3.1, df48, n=53, p=0.03[1] 95% CI -21.0, -4.6
	LBP last 3 months	t=-7.6, df103, n=109, **p≤0.001*** ** 95% CI -25.5, -15.0	t=-2.8, df46, n=49, **p=0.006** ** 95% CI -20.2, -3.5
UK	Pain in general	t=-3.4, df81, n= 85, **p≤0.001*** ** 95% CI -18.6, -5.0	t=-0.4, df10, n=12, p=0.67 95% CI -32.0, 21.5
	Back pain	t=-4.4, df70, n=72, **p≤0.001*** ** 95% CI -22.3, -8.4	t=-0.8, df18, n=22, p=0.42 95% CI -17.6, 7.8
	MSKP	t=-4.4, df70, n=39, **p≤0.001*** ** 95% CI -22.3, -8.4	t=-8.1, df18, n=54, p=0.42 95% CI -17.6, 7.8
	LBP lifetime	t=-3.6, df70, n=72, **p≤0.001*** ** 95% CI -21.1, -6.2	t=-0.49, df21, n=25, p=0.62 95% CI -14.1, 8.7
	LBP current	t=-3.6, df70, n=66, **p≤0.001*** ** 95% CI -21.1, -6.2	t=-0.49, df21, n=28, p=0.62 95% CI -14.1, 8.7
	LBP last 1 month	t=-4.4, df66, n=68, **p≤0.001*** ** 95% CI -23.4, -8.8	t=-0.51, df22, n=26, p=0.61 95% CI -13.5, 8.1
	LBP last 3 months	t=-4.4, df66, n=68, **p≤0.001*** ** 95% CI -23.4, -8.3	t=-0.51, df22, n=26, p=0.61 95% CI 13.5, 8.1
		UK	
USA	Pain in general	t=-2.48, df155, n=157, p≤0.01[1] 95% CI -8.9, -1.0	U=3.00, p=0.24 n=9
	Back pain	t=-2.09, df126, n=128, p=0.03[1] 95% CI -8.8, -0.2	t=-1.76, df34, n=36, p=0.08 95% CI -16.7, 1.18
	MSKP	t=0.2, df62, n=64, p=0.82 95% CI -5.2, 6.5	t=-4.3, df97, n=99, **p≤0.001*** ** 95% CI -15.5, -5.7
	LBP lifetime	t=-1.96, df121, n=123, p=0.051 95% CI -8.7, 0.02	t=-2.21, df41, n=43, p=0.03[1] 95% CI -17.2, -0.7
	LBP current	t=-1.39, df107, n=109, p=0.16 95% CI -8.05, 1.4	t=-2.7, df48, n=50, p=0.008[1] 95% CI -17.2, -2.7
	LBP last 1 month	t=-1.3, df109, n=111, p=0.16 95% CI -7.9, 1.1	t=-2.74, df48, n=50. p=0.008[1] 95% CI -17.5, -2.7
	LBP last 3 months	t=-1.3, df109, n=111, p=0.16 95% CI -7.9, 1.3	t=-02.74, df48, n=50, p=0.008[1] 95% CI -17.5, -2.7

[1]not significant post Bonferroni correction; **Significant at p≤0.01 level, ***Significant at p≤0.001 level, **in bold:** significant following application of the Bonferroni correction.

Abbreviations: MSKP, Musculoskeletal Pain; LBP, Low Back Pain.

Statistical test: t, Independent t-test.

9.1.7 Pain and LBP across nations; relation to pain/LBP days, pain free periods, onset

The USA and UK groups had very similar reports on the number of pain and LBP days felt each month which was similar to that reported by the pooled group examined in Chapter 6. For both countries the vast majority of respondents felt pain or LBP daily. However, the reports by Greeks were different as just over 20% of Greeks reported daily pain and an even lower percentage reported daily LBP. Greeks mainly felt pain or LBP between 1-9 and 10-20 days per month (Figures 9.1.1, 9.1.2; Appendix 9: Table 9.a.4.1).

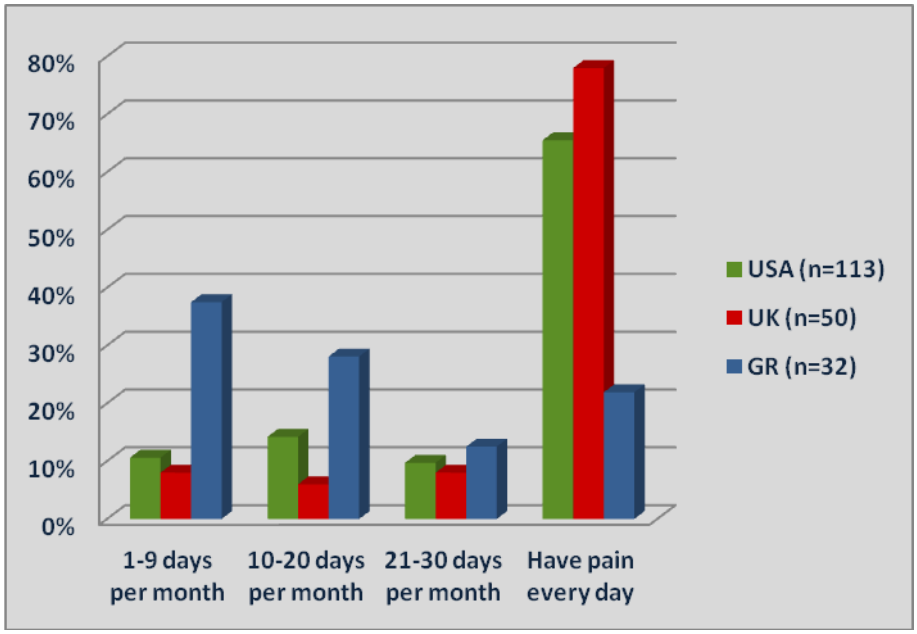

Figure 9.1.1: Percentage of people reporting the number of days they feel pain per month across nation. People with no pain or who could not remember were excluded.

Earlier, using the pooled data (Chapter 6), it was found that people with and without MSKP feel pain in general for a similar number of days throughout the month. This result was maintained within each individual national group (Appendix 9: Table 9.a.4.2).

The USA and the UK groups were very similar in how often they had a break from pain in general or LBP in particular; pain was constant for most participants. For Greeks, the frequency of pain and LBP breaks was more regular (Figures 9.1.3 and 9.1.4; Appendix 9: Table 9.a.4.3).

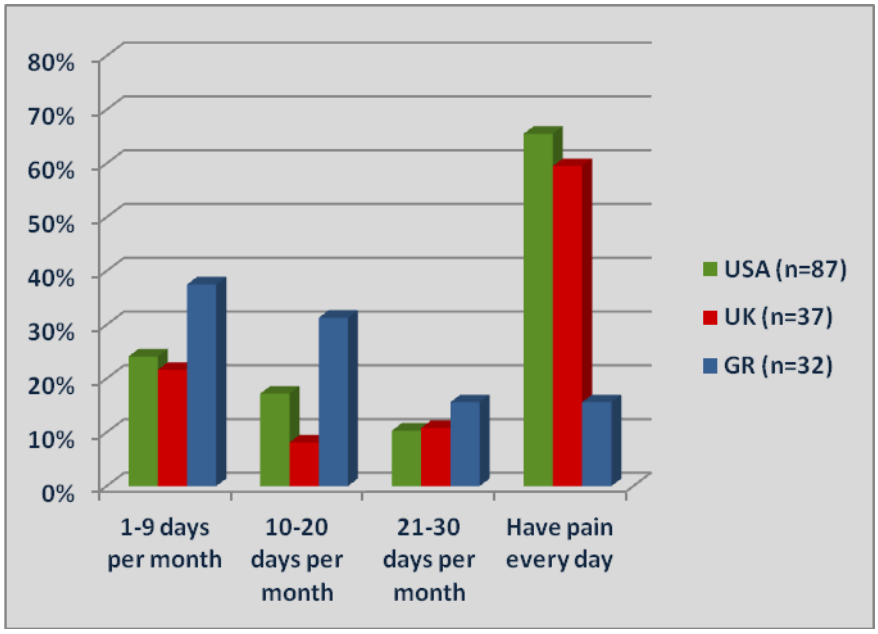

Figure 9.1.2: Percentage of people reporting the number of days they feel LBP per month across nations. People with no pain or who could not remember were excluded.

Overall, the same pain and LBP onset times post iSCI were noticed within each individual country group as for the pooled group which was examined earlier (Chapter 6, Section 6.1.8). Though Greeks reported a higher proportion of pain/LBP onset at between 1-6 months post iSCI rather than immediately post iSCI as the USA and UK groups did (Figure 9.1.5, 9.1.6; Appendix 9: Table 9.a.4.4).

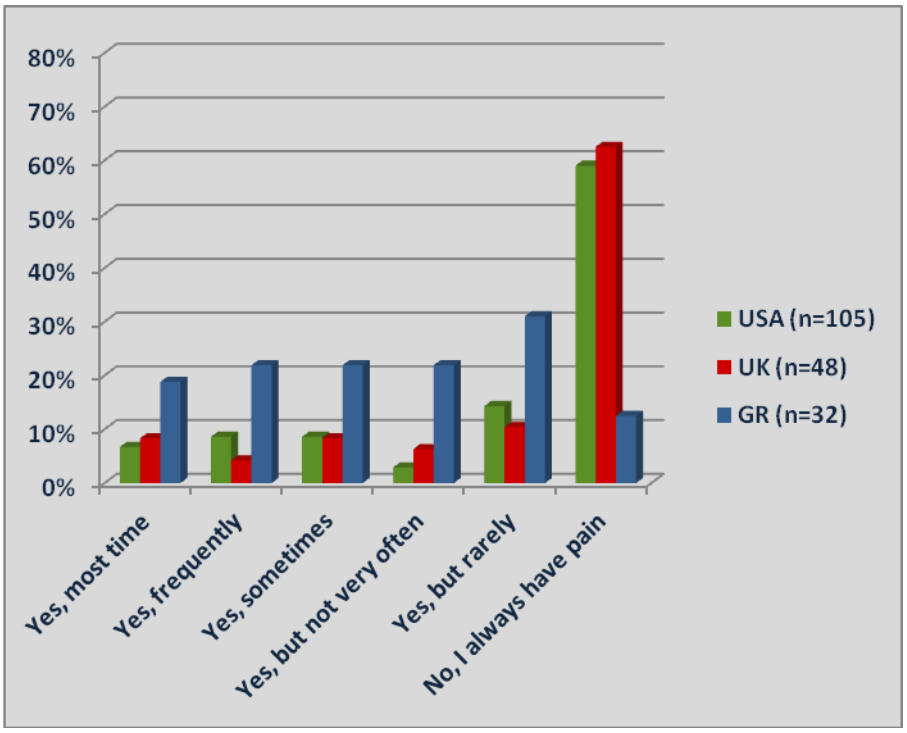

Figure 9.1.3: Percentage of people reporting the frequency of their pain-free weeks across nations

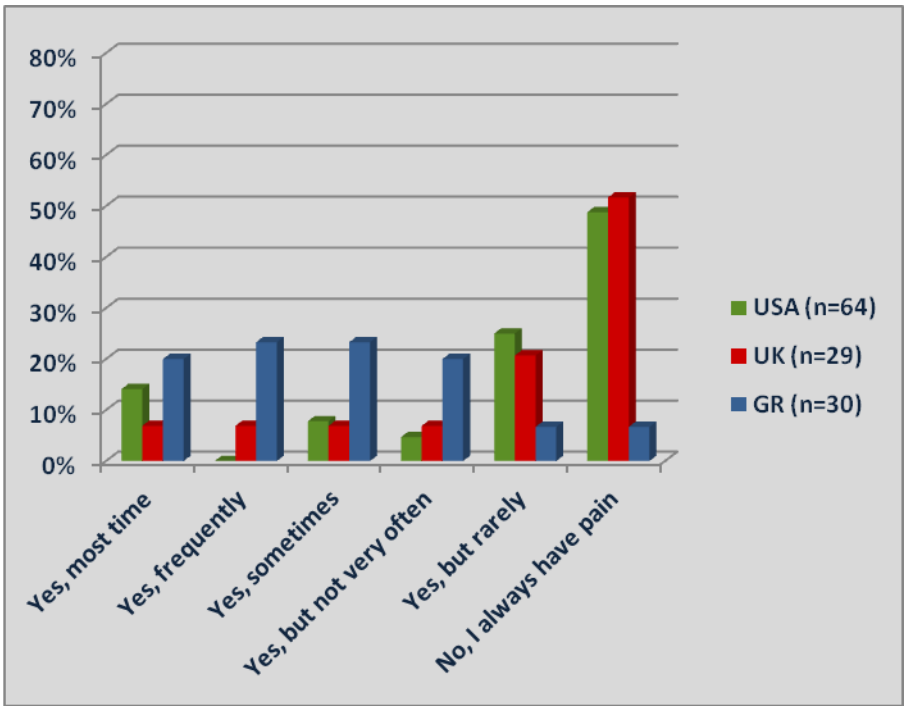

Figure 9.1.4: Percentage of people reporting the frequency of their LBP-free weeks across nations

In Chapter 6 (Section 6.1.8) LBP onset was examined between people with different causes of injury. This was done to check for similarities with the only other study which reported on LBP onset post SCI in the literature.[371] The findings in this study for the pooled data differed to that of Raissi et al.[371] The group examined by Raissi et al[371] was from Iran. Examining each individual group from the three participating countries looking at people with a traumatic onset to their injury (as in Raissi et al[371]), LBP onset immediately after iSCI was much lower than in Raissi et al.[371] Differences in the onset of LBP between people with traumatic and non-traumatic injury is presented in Appendix 9: Table 9.a.4.5.

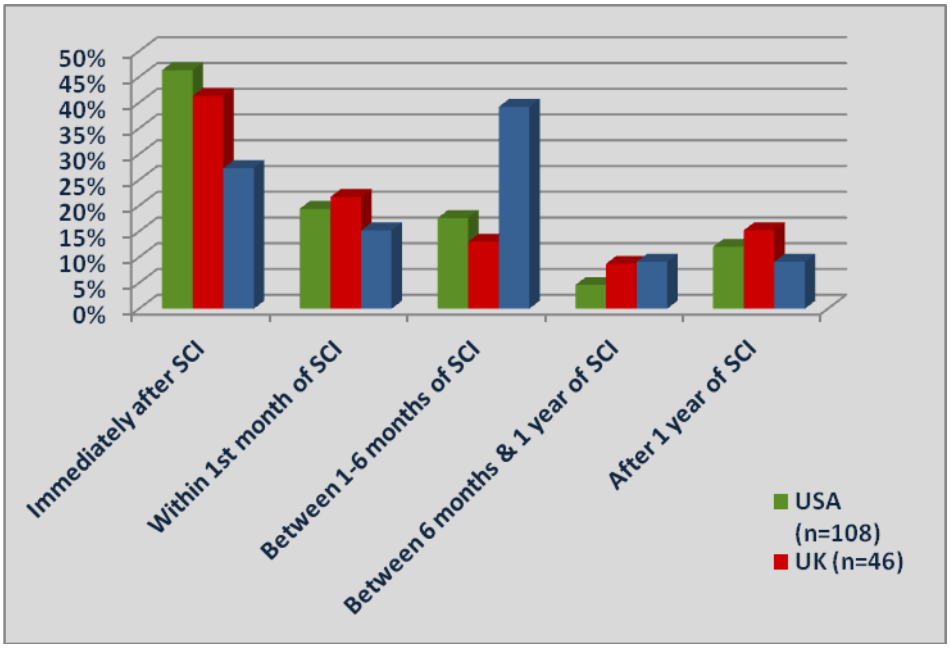

Figure 9.1.5: Percentage of people reporting the onset of their pain post iSCI across nations
Abbreviations: iSCI, incomplete Spinal Cord Injury.

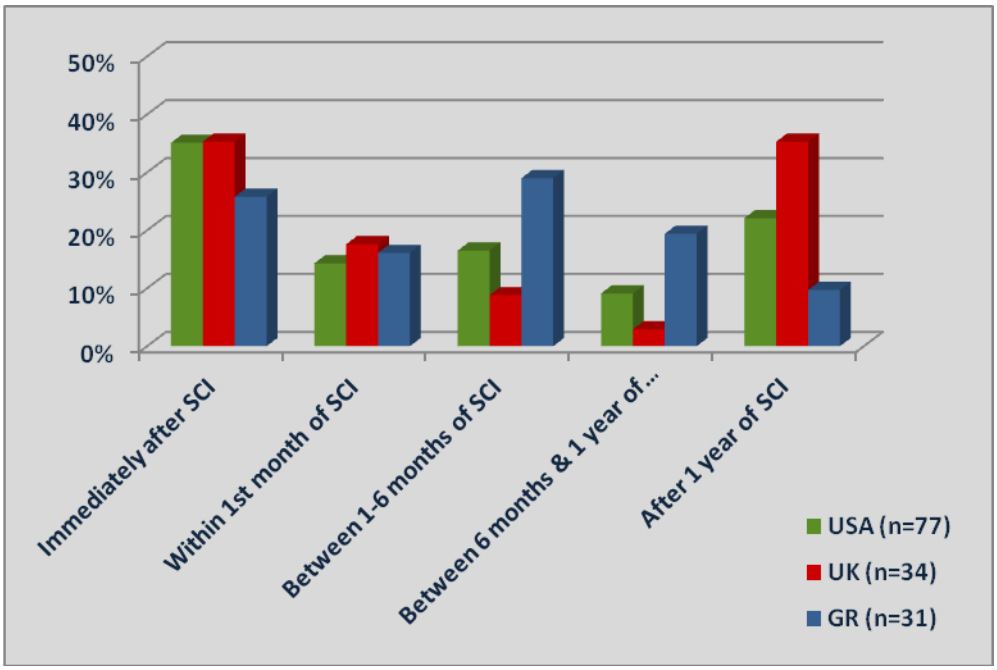

Figure 9.1.6: Percentage of people reporting the onset of their LBP post iSCI across nations
Abbreviations: iSCI, incomplete Spinal Cord Injury.

Part of the second hypothesis theme has been the examination of the correlation between the onset of pain/LBP post iSCI and the number of pain/LBP days (respectively) felt per month. In Chapter 6, for the pooled group, it was found that the earlier the onset of pain or LBP, the significantly more the painful days. The correlation for LBP was stronger. The same correlation was examined per country as follows:

Hypothesis 0 (null): In people with iSCI there is no significant correlation between pain or LBP onset post iSCI and the number of pain or LBP days felt in a month for each national group.

Hypothesis 4a: In people with iSCI there is a significant correlation between pain onset post iSCI and the number of pain days felt in a month for each national group.

Hypothesis 4b: In people with iSCI there is a significant correlation between LBP onset post iSCI and the number of LBP days felt in a month for each national group.

Among people with pain, the correlation between pain onset and pain days within each country group was negative, thus the earlier the onset of pain, the more the pain

days felt in the month, but in no case was this statistically significant. The strength of the correlation for the UK group was moderate making it the strongest correlation (Table 9.1.8). In the case of LBP onset post iSCI, the earlier the onset, the more LBP days felt in the month for Greeks and for people from the USA. For the latter, the strength of the correlation was strong and statistically significant.

For each individual group from the three countries there was no significant correlation between the onset of pain post iSCI and the number of pain days (Table 9.1.8), despite the fact that when the total number of respondents were previously pooled together (Chapter 6) this correlation was statistically significant (p=0.04). In the case of a correlation between LBP onset post iSCI and LBP days for the USA and UK, the earlier the LBP onset, the more LBP days were felt per month (p≤0.001, Table 9.1.8). This was not found for the Greek group.

Table 9.1.8: Correlation between pain/LBP onset post iSCI and pain/LBP days per each national group

Correlations	USA Statistical test	UK Statistical test	Greece Statistical test
Pain onset post iSCI and pain days	p=0.054 γ=-0.25, n=108	p=0.06 γ=-0.49, n=46	p=0.97 γ=0.007, n=32
LBP onset post iSCI and LBP days	**p≤0.001***** γ=-0.51, n=74	p=0.41 γ=-0.20, n=32	p=0.43 γ=-0.17, n=31

***Significant at p≤0.001 level; **in bold:** significant following application of the Bonferroni correction
Abbreviations: iSCI, incomplete Spinal Cord Injury; LBP, Low Back Pain.
Statistical test: γ, Gamma test.

Part 2; Pain extent and LBP experience across the countries

9.2.1 Introduction

So far this chapter has described the demographic profile characteristics of the respondents from the three participating countries. It has explored the pain presence for each individual group and compared for differences or similarities within and between the country groups. This second part of the chapter will investigate the quality and intensity of LBP, and the pain extent that people within each country group report. Comparisons with the results from the pooled data examined in the previous chapters will be made.

9.2.2 Bonferroni Correction

In the current part of the analysis the number of multiple tests done on the variables of interest was n=14 thus the α-level of statistical significance set by Bonferroni was p≤0.0035 (Appendix 9: Table 9.b.1.1).

9.2.3 Pain extent across nations; general results

As explained in Chapter 6 (Section 6.2.3), the body chart used was divided into nine areas. The groups from the three countries showed very similar results in their mean number of painful areas and no significant differences between the groups were found (p=0.13, H=4.07, Kruskal-Wallis, n=190) (Appendix 9: Table 9.b.2.1).

For respondents for all three countries, the lower back midline area was the most common area with pain in the back similar to the pooled data (Chapter 6). One difference was that people from the UK reported less cases of upper back pain, mainly at the right and left side compared to the other two countries (Table 9.2.1). Pain at the

buttocks was highly reported by people from all countries, mostly however by the UK group.

Table 9.2.1: Distribution of pain presence for the back and buttocks across nations

Pain on back area and buttocks	**USA** (%, n) Total n=110	**UK** (%, n) Total n=50	**GR** (%, n) Total n=43
Back area	81.8 (n=90)	81.0 (n=39)	100 (n=32)
Upper back right side	13.6 (n=15)	4.2 (n=2)	12.5 (n=4)
Upper back left side	10.9 (n=12)	4.2 (n=2)	15.6 (n=5)
Upper back midline	17.3 (n=19)	8.3 (n=4)	25.0 (n=8)
Lower back right side	17.3 (n=19)	27.1 (n=13)	40.6 (n=13)
Lower back left side	20.0 (n=22)	22.9 (n=11)	43.7 (n=14)
Lower back midline	35.5 (n=39)	41.2 (n=20)	53.1 (n=17)
Buttocks	54.5 (n=60)	62.5 (n=30)	53.1 (n=17)
Right buttock	30.0 (n=33)	35.4 (n=17)	25.0 (n=8)
Left buttock	27.3 (n=30)	37.5 (n=18)	34.4 (n=11)
Midline area buttock (including anus)	33.6 (n=37)	43.7 (n=21)	25.0 (n=8)

The 9-areas body chart division was used in this analysis

People from all countries described their pain at the back area in fairly similar ways, mainly as an internal pain and, in particular, this was the description for the lower back midline area (Appendix 9: Figure 9.b.2.1). Pain at the buttocks slightly varied across the countries (Appendix 9: Figure 9.b.2.2).

9.2.4 Pain extent across nations; relation to LBP and MSKP

Using data from the pooled group it was found that people with LBP (any time period) and people with MSKP reported a significantly higher mean number of areas with pain compared to people without these types of pain (Chapter 6, Section 6.2.4). The same relation was examined per country and it was found that the results from the USA were significant (Table 9.2.2; Appendix 9: Table 9.b.3.1).

Table 9.2.2: Differences in the mean number of areas with pain in groups with and without LBP or MSKP within each national group

	USA	UK	Greece
	Statistical Test	Statistical Test	Statistical Test
Lifetime LBP	U=225.5, n=110 **p≤0.001*** **	U=108, n=48 p=0.03[1]	U=15.5, n=32 p=0.12
Current LBP	U=422.5, n=107 **p≤0.001*** **	U=130, n=47 p=0.04[1]	U=28.5, n=32 p=0.29
LBP presence over last 1 month	U=516, n=109 **p≤0.001*** **	U=14.5, n=47 p≤0.03[1]	U=15.5, n=32 p=0.24
LBP presence over last 3 months	U=410.5, n=106 **p≤0.001*** **	U=114.5, n=47 p≤0.03[1]	U=15.5, n=32 p=0.25
MSKP	U=799, n=110 **p≤0.001*** **	U=178.5, n=47 p=0.03[1]	U=76.5, n=31 p=0.25

[1]not significant post Bonferroni correction; ***Statistically significant at p≤0.001 level;
in bold: significant following application of the Bonferroni correction.
Abbreviations: LBP, Low Back Pain; MSKP, Musculoskeletal Pain
Statistical test: U, Mann-Whitney U test

9.2.5 Pain extent across nations; relation to demographic profile characteristics

When examining pain extent in relation to the demographic profile characteristics using the pooled data, the only significant difference found was between males and females (Chapter 6, Section 6.2.5). Investigating each national group separately, no difference passed the Bonferroni α-level of significance, including the gender difference. This indicates that a larger group may be needed in order to identify any such differences for pain extent (Appendix 9: Tables 9.b.4.1 and 9.b.4.2).

Because pre-Bonferroni application a difference in sex and the number of areas with pain was noticed this was examined further and it is presented at Appendix 9: Tables 9.b.4.3 and 9.b.4.4.

9.2.6 Pain extent across nations; relation to pain/LBP days, free periods, onset

Earlier analysis showed that for the pooled group, those who reported more areas with pain also reported significantly more pain days felt in the month (Chapter 6, Section 6.2.6). For the USA group, more areas with pain correlated significantly with increased pain days ($p \leq 0.001$, $\rho = 0.31$, Spearman's, $n = 110$) but not LBP days. No such significant correlation was found for the other two countries although they had the same direction (Appendix 9: Table 9.b.5.1).

For the pooled group (Chapter 6, Section 6.2.6), it was also found that the more the areas with pain, the less frequent the pain-free weeks. However, no such correlation was found for any individual country (Appendix 9: Table 9.b.5.2).

As part of the second hypothesis theme for the total respondents group, it was found that the earlier the onset of pain or LBP post iSCI, the more the number of areas with pain but the correlation was not statistically significant (Chapter 6, Section 6.2.6). This hypothesis (hypothesis 6) was examined individually for each group from the three countries.

Hypothesis 0 (null): In people with iSCI there is no significant correlation between the number of areas with pain and the onset of pain or LBP post iSCI for each national group.

Hypothesis 6: In people with iSCI there is a significant correlation between the number of areas with pain and the onset of pain or LBP post iSCI for each national group.

Spearman's correlation was applied on the data and no significant results were found. The direction of the correlations were negative, thus the earlier the pain or LBP onset post iSCI, the more the painful areas (Tables 9.2.3 and 9.2.4).

Table 9.2.3: Mean number of areas with pain in groups divided by the time of pain onset post iSCI. Correlations between the number of areas with pain and pain onset within each national group

	USA		UK		Greece	
	Mean, median, min-max	Statistical Test	Mean, median, min-max	Statistical Test	Mean, median, min-max	Statistical Test
Immediately after iSCI	3.7±2.1 3.5, 1-9 n=48	ρ=-0.15 p=0.11 n=105	3.9±1.4 4, 1-6 n=18	ρ=-0.11 p=0.46 n=44	3.9±2.4, 3 1-9, n=9	ρ=-0.13 p=0.45 n=32
Within 1 month post iSCI	3.0±1.7 3.0, 1-8 n=21	95%CI -0.31, 0.02	3.8±1.3 4, 2-6 n=10	95%CI -0.38, 0.18	2.8±1.3, 2 2-5, n=5	95%CI -0.11, 0.22
Between 1-6 months post iSCI	2.8±1.5 2, 1-6 n=19		3.7±1.9 3.5, 2-7 n=6		3.1±1.0, 3 1-5, n=12	
Between 6 months & 1 year post iSCI	3.4±1.3 4, 2-5 n=5		2.7±0.5 3,2, 1-3 n=4		3.0±1.7, 3 1-4, n=3	
After 1 years post iSCI	2.8±1.6, 2, 1-6, n=12		4.2±2.1, 4, 2-7, n=6		2.3±1.2, 3, 1-3, n=3	

Abbreviations: iSCI, incomplete Spinal Cord Injury.
Statistical test: ρ, Spearman's rank correlation rho.

Table 9.2.4: Number of areas with pain in groups divided by LBP onset post iSCI. Correlations between the number of areas with pain and LBP onset within each national group

	USA		UK		Greece	
	Mean, median, min-max	Statistical Test	Mean, median, min-max	Statistical Test	Mean, median, min-max	Statistical Test
Immediately after iSCI	4.0±1.7 4, 1-8 n=26	ρ=-0.17 p=0.15 n=71	3.8±1.5 4, 1-6 n=12	ρ=-0.01 p=0.94 n=34	3.1±1.6, 3 1-6, n=7[1]	ρ=-0.09 p=0.64 n=28
Within 1 month post iSCI	3.3±1.3 3.5, 1-5 n=10	95%CI -0.30, 0.11	4.2±1.5 4.5, 2-6 n=6	95%CI -0.33, 0.31	3.2±1.3, 3 2-5, n=5	95%CI -0.49, 0.21
Between 1-6 months post iSCI	3.5±1.5 4, 2-7 n=15		3.7±2.9 2, 2-7 n=3		3.4±0.7, 3 1-5, n=9	
Between 6 months & 1 year post iSCI	4.0±1.3 4.5, 2-5 n=6		n=1		2.8±1.3, 3 1-4, n=5	
After 1 years post iSCI	3.1±1.5 3, 2-6 n=14[1]		4.0±1.4 4, 2-7 n=12		2.0±1.4, 2 1-3, n=2	

[1]One outlier eliminated from analysis.
Abbreviations: iSCI, incomplete Spinal Cord Injury.
Statistical test: ρ, Spearman's rank correlation rho.

9.2.7 LBP quality and intensity across nations; general results

During the pooled group analysis it was shown that respondents used all verbal descriptors to describe their pain; primarily using "aching" which ranked as of moderate intensity (Chapter 6, Section 6.2.7). Examining the groups by country (Appendix 9, Tables 9.b.7.1, 9.b.7.2), it was noted that all three countries reported all verbal descriptors to some extent; "splitting" being less reported by the Greek group (19.4%), while "aching" was very frequently and similarly reported by both the USA and UK groups (86.5% and 84.3%, respectively). For the USA group "aching" was mainly a moderate pain (48.2%) but for the UK group it was mainly a severe pain (40.5%). People from Greece reported "gnawing" as the most frequent type of pain (64.5%), which was mainly a mild pain (41.9%). The mean number of words chosen was also looked at and people from the UK used the most words to describe their LBP quality (Table 9.b.7.3).

People from Greece reported a lower mean quality of LBP for all dimensions (sensory, affective and total PRI) particularly for the S-PRI and total PRI but the differences did not pass the Bonferroni α-level of significance (Table 9.2.5).

Table 9.2.5: Mean LBP quality in groups across nations. Differences between national groups

	USA mean±SD, n	UK mean±SD, n	Greece mean±SD, n	Between counties Statistical Tests
S-PRI	10.3±7.1 n=83	12.5±9.3 n=38	6.7±5.5 n=29	F=5.44, df2, p=0.005 [1]
A-PRI	3.4±3.4 n=83	3.9±3.8 n=38	2.5±3.6 n=29	F=1.2, df2 p=0.3
Total PRI	13.7±10.0 n=82	14.9±11.3 n=36	9.2±8.2 n=31	F=3.07, df2 p=0.04 [1]

[1]not significant post Bonferroni correction.
Abbreviations: PRI, Pain Rating Index.
Statistical test: F, One-way ANOVA.

Investigating LBP intensity per group, the UK was the group with the highest intensity for LBP time periods (current, usual over last one month, usual over last three months)

but the mean differences between the countries were not large. One-way ANOVA confirmed the similarities between the three groups on LBP intensity (Table 9.2.6).

The Greek group only had three responses[35] to this question so reliability in this case is limited.

Table 9.2.6: Mean LBP intensity in national groups

	USA mean±SD, n	UK mean±SD, n	Greece mean±SD, n	Statistical Test
Current LBP intensity (0-100 NRS)	41.3±27.9 n=85	46.7±29.5 n=36	45.0±31.2 n=3	F=0.46, df2 p=0.62, n=124
Intensity LBP last 1 month (0-100 NRS)	45.2±27.3 n=85	51.8±26.5 n=34	47.0±33.9 n=3	F=0.71, df2 p=0.49, n=122
Intensity LBP last 3 months (0-100 NRS)	46.2±26.4 n=84	53.0±27.7 n=34	40.0±32.8 n=3	F=0.90, df2 p=0.40, n=121

Abbreviations: LBP, Low Back Pain; NRS, Numeric Rating Scale.
Statistical test: F, One-way ANOVA.

In the case of overall evaluative intensity of LBP (PPI), people from each country individually reported similar results, however a higher proportion of people from the UK felt discomforting LBP (Figure 9.2.1). Converting the evaluative intensity scale into a mean score it was clear that people from the three nations reported similar means; USA 2.4±0.9, UK 2.3±1.0 and GR 2.1±0.8 which did not differ statistically (p=0.52, F=0.64, n=141).

[35] For an explanation of why the NRS responses for Greece are so limited see Chapter 6, Section 6.2.7.

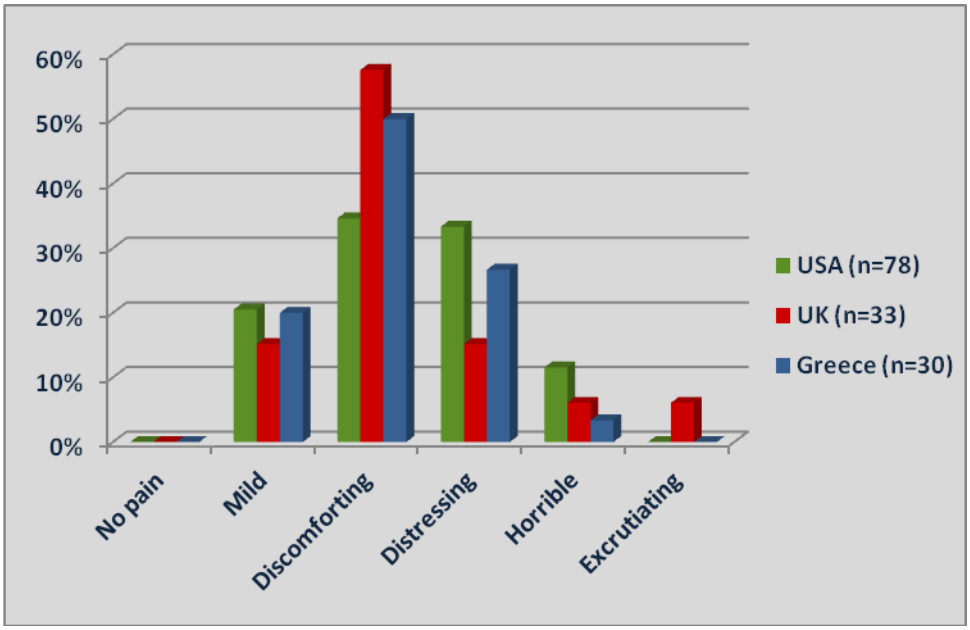

Figure 9.2.1: Percentage of people reporting their evaluative overall LBP intensity within each national group

9.2.8 LBP quality and intensity across nations; relation to demographic profile characteristics

The interaction effect between the country and another IV which changed every time (e.g. sex, type of injury etc) on the outcome of interest (DV) which also changed was examined using two-way ANOVA. The aim remained to investigate the role of the country of residence on the outcome as a co-effect.

9.2.8.1 Gender across nations

No significant interaction effect between country of residence and gender on sensory, affective or total quality of LBP (PRI) was found (Appendix 9: Table 9.b.6.1). Similarly, there was no interaction effect of these two variables on LBP intensity (all time periods) (Appendix 9: Table 9.b.6.1). Overall, examining the groups *between* the three countries, males from the UK reported the worst quality of LBP. Also it was noticed that males from Greece reported the most severe LBP intensity, but as this group was very small results may not be reliable. *Within* the groups from each country males and

females did not differ significantly in their mean reports either for the quality or the intensity of their LBP which was similar to the results found earlier for the pooled group (Appendix 9: Table 9.b.6.1). Further two-group comparisons were conducted between groups that could possibly differ but did not reveal any significant differences (Appendix 9: Table 9.b.6.2).

9.2.8.2 Cause of injury across nations

Analysis showed that there was no significant interaction effect between cause of injury and country on the quality or the intensity of LBP and the effect sizes $(\eta^2)_{36}$ were small (Appendix 9: Table 9.b.6.4). People from Greece reported the best quality for their LBP and people from the UK the worst. Two-group comparisons were made between groups that seemed to have distant means and some significant differences were found (Appendix 9: Table 9.b.6.4). Finally, within the groups from all three countries, people with traumatic and non-traumatic cause for their injury did not differ significantly in the quality of LBP and usually those with a non-traumatic cause had a slightly worse total mean score (Appendix 9: Table 9.b.6.4).

9.2.8.3 Level of injury across nations

The interaction effect between country of residence and level of injury was not significant on the quality or the intensity of LBP (Table 9.2.7). Earlier analysis in Chapter 6, Section 6.2.8 showed that people with paraplegia reported significantly worse LBP quality (sensory and affective dimension) and intensity of LBP was higher but not significantly different compared to people with tetraplegia. Between the groups from the three countries people from Greece reported the best quality of LBP. Additional two-group comparisons identified differences between the subgroups of the compared national groups (Appendix 9: Table 9.b.6.5). Separate, within country group analysis showed that only within the USA group people with paraplegia reported

[36] For details on the effect sizes refer back Chapter 5, Section 5.21.

significantly worse LBP quality and LBP intensity compared to people with paraplegia (Table 9.2.7).

Table 9.2.7: Differences in LBP quality or intensity between groups divided by level of injury (paraplegia and tetraplegia), within each national group. Interaction effect of country of residence and level of injury on LBP intensity and quality

	Comparisons within each country			Effect of level of injury *country on DV
	USA	**UK**	**GR**	
S-PRI	U=445 **p≤0.001*****	t=-1.00, df36, p=0.32 95% CI -9.4, 3.1	U=769.5 p=0.58	F=2.68, p=0.07, η^2=0.0109 n=152
A-PRI	U=551.5 p=0.008[1]	U=152.5 p=0.63	U=78.5 p=0.91	F=1.59, p=0.20, η^2=0.0108 n=150
Total PRI	U=433.5 **p≤0.001*****	t=-1.17, df34, p=0.24 95% CI -12.5, 3.3	U=68.5 p=0.55	F=2.12, p=0.12, η^2=0.0098 n=148
Intensity of current LBP	t=-2.23, df83, p=0.02[1] 95% CI -25.1, 1.4	t=-0.09, df34, p=0.92 95% CI -22.4, 20.4	n/a	F=1.94, p=0.14, η^2=0.0095 n=122
Intensity of LBP over last 1 month	t=-2.90, df83, p=0.005[1] 95% CI -20.0, 6.1	t=0.18, df32, p=0.85 95% CI -17.8, 21.4	n/a	F=2.96, p=0.055 η^2=0.0117 n=120
Intensity of LBP over last 3 months	t=-3.54, df82, **p≤0.001***** 95% CI -30.0, 8.4	t=0.05, df32, p=0.95 95% CI -19.9, 21.1	n/a	F=3.011, p=0.053, η^2=0.01109 n=119
Evaluative PPI of LBP	t=-2.66, df76, p=0.009[1] 95% CI -0.9, 0.1	t=0.28, df29, p=0.78 95% CI -0.5, 0.6	U=76.5 p=0.83	F=1.87, p=0.15, η^2=0.00335 n=139

[1]not significant post Bonferroni correction; **in bold:** significant following application of the Bonferroni correction.
Abbreviations: PRI, Pain Rating Index; S-PRI, Sensory PRI; A-PRI, Affective PRI; LBP, Low Back Pain; PPI, Present Pain Intensity.
Statistical tests: U, Mann-Whitney U test; t, Independent t-test; F, Two-way ANOVA.

9.2.8.4 Age across nations

Previous analysis for the pooled group found that as age increased the total PRI improved and age did not correlate with the intensity of LBP (Chapter 6, Section 6.2.8). Using regression analysis to examine the interaction effect of age and country of

residence on quality and intensity of LBP for two cases, it was found statistically significant but failed to pass the Bonferroni α-level of significance (Table 9.2.8). Age did not correlate significantly with quality of LBP within any national groups although an increase in age correlated with an improvement in LBP quality but the correlations were of small strength. Also, the correlation between age and LBP intensity was weak and not significant though it was stronger for the UK group (Appendix 9: Table 9.b.6.6).

9.2.8.5 Time since injury across nations

Examining the pooled data earlier, no significant correlations between the time since injury and quality or intensity of LBP were found (Chapter 6, Section 6.2.8). Using regression, no effects were found between the time since injury and the country of residence on either the quality or the intensity of LBP that passed the Bonferroni α-level of significance. Finally, no significant correlations were found between time since injury and quality or intensity of LBP for any group per each individual nation (Appendix 9: Table 9.b.6.6).

9.2.9 LBP quality and intensity across nations; pain/LBP days, free periods, onset

Earlier analysis showed that as the number of LBP days felt in a month increased, the quality of LBP decreased (Chapter 6, Section 6.2.9). Using two-way ANOVA to examine the interaction effect of the country of residence and the number of LBP days felt in a month on any of the PRI dimensions of LBP, no significant results were found (Table 9.2.8). Looking at the data from individual groups, however, it was found that within the USA group worse LBP quality correlated significantly with earlier LBP onset but not earlier pain onset (Appendix 9: Table 9.b.8.1). The significant relationship found previously that the more the LBP days, the higher the intensity of LBP maintained its significance within both the USA and UK groups (Appendix 9: Table 9.b.8.1). Though an increased number of pain days correlated with LBP intensity, the correlation was not

significant but there were occasions where the correlation had moderate strength (Appendix 9: Table 9.b.8.1).

Table 9.2.8: Interaction effects of country of residence and age or time since injury on LBP quality and intensity

	Effect of age *country on DV	Effect of time since injury *country on DV
S-PRI	p=0.005[1] df3, n=148 Wald χ^2=12.72, Likelihood ratio χ^2=12.2 p=0.007[1]	p=0.01[1] df3, n=151 Wald χ^2=11.09, Likelihood ratio χ^2=10.7, p=0.01[1]
A-PRI	p=0.26, df3, n=148 Wald χ^2=3.91, Likelihood ratio χ^2=3.92 p=0.26	p=0.28, df3, n=151 Wald χ^2=3.80, Likelihood ratio χ^2=3.75 p=0.28
Total PRI	p=0.02[1] df3, n=145 Wald χ^2=9.25, Likelihood ratio χ^2=8.97 p=0.03[1]	p=0.01[1] df3, n=148 Wald χ^2=10.25, Likelihood ratio χ^2=9.91, p=0.01[1]
Intensity of current LBP[¥]	p=0.62, df3, n=116 Wald χ^2=0.74, Likelihood ratio χ^2=0.73 p=0.69	p=0.21, df3, n=120 Wald χ^2=3.07, Likelihood ratio χ^2=3.03, p=0.21
Intensity of LBP over last 1 month[¥]	p=0.61, df3 Wald χ^2=0.97, Likelihood ratio χ^2=0.96 p=0.61	p=0.01[1] df3, n=118 Wald χ^2=6.94, Likelihood ratio χ^2=6.75, p=0.03[1]
Intensity of LBP over last 3 months[¥]	p=0.66, df3, n=114 Wald χ^2=0.81, Likelihood ratio χ^2=0.81 p=0.66	p=0.01[1] df3, n=117 Wald χ^2=8.83, Likelihood ratio χ^2=8.51, p=0.01[1]
Evaluative PPI of LBP	p=0.23, df12 Likelihood ratio χ^2=15.13, Nagelkerke R^2=0.11	p=0.11, df12 Likelihood ratio χ^2=17.89, Nagelkerke R^2=0.11

[¥]The Greek group was excluded due to insufficient data; [1] not significant post Bonferroni correction.

Abbreviations: MSKP, Musculoskeletal Pain; LBP, Low Back Pain; SE, Standard Error; OR, Odd Ratio;

Statistical tests: χ^2, Likelihood ration Chi-square; Wald test chi-square distribution; R^2, Nagelkerke R square (pseudo-R).

The frequency of having pain- or LBP-free weeks was examined aiming to investigate if that would lead to less severe LBP. No significant interaction effect between pain- or LBP-free weeks and the country of residence was found on either the quality (any dimensions) or the intensity of LBP (Table 9.2.8). In addition, within each country group the frequency of pain-free weeks did not correlate with the quality of LBP and

though the correlation was stronger for LBP-free weeks, they also did not pass the Bonferroni α-level of significance (Appendix 9: Table 9.b.8.2). The impact of the persistence of pain and LBP was greater on the intensity of LBP, particularly for the USA and UK groups, where the correlations were strong and statistically significant (Appendix 9: Table 9.b.8.2).

Using the pooled data in earlier analysis it was found that worse LBP quality and intensity correlated significantly with earlier LBP onset following iSCI but not with earlier pain (in general) onset (Chapter 6, Section 6.2.9). Using two-way ANOVA to examine the interaction effect of the country of residence and the onset of LBP on either the PRI dimensions of LBP or its intensity, no results passed the Bonferroni α-level of significance (Table 9.2.8). In the case of the interaction effect of these variables on the affective dimension, the results were not far from the Bonferroni significance (p=0.005, F=2.96, Two-way ANOVA, n=135). Figure 9.2.2 shows this interaction as the lines representing each variable cross with each other. But as the significance did not pass the Bonferroni level it is not accepted here as a significant interaction effect but it may be considered for future studies. More interaction effect results are in Table 9.2.9.

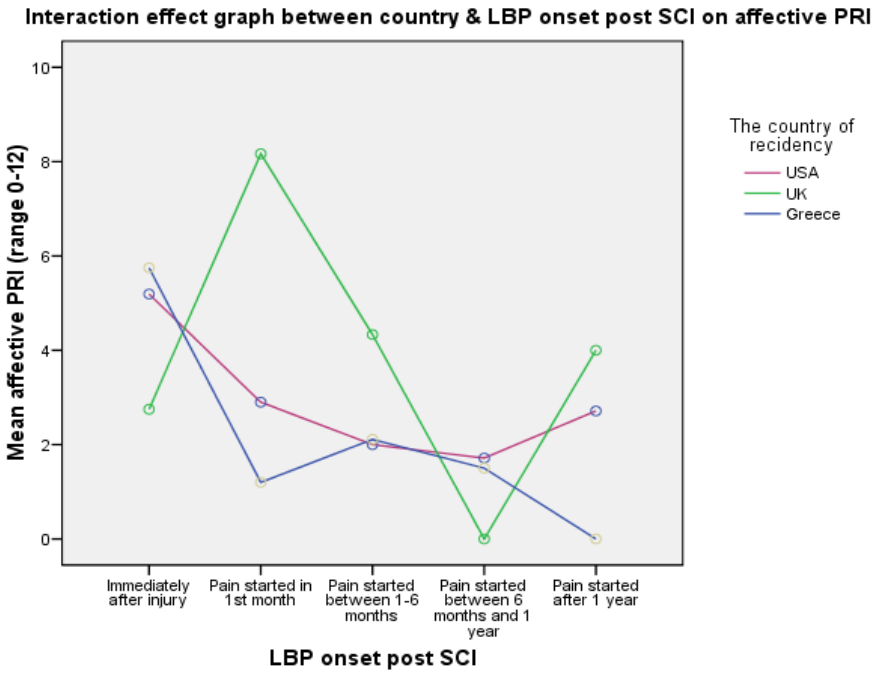

Figure 9.2.2: Graph showing the significant interaction effect between country of residence and LBP onset post iSCI on affective dimension (n=135). Abbreviations; PRI, Pain Rating Index; LBP, Low Back Pain; iSCI, incomplete Spinal Cord Injury.

Table 9.2.9: Interaction effects of country of residence and another variable on LBP quality and intensity

	Effect of number of LBP days *country on DV	Effect of number of LBP free weeks *country on DV	Effect of number of LBP onset post iSCI *country on DV
S-PRI	F=0.78, p=0.58, η^2=0.0101 n=142	F=0.42, p=0.91, η^2=0.0100 n=119	F=1.88, p=0.068, η^2=0.0342 n=135
A-PRI	F=3.81, p=0.10, η^2=0.00348 n=142	F=0.90, p=0.52, η^2=0.0317 n=119	F=2.96, p=0.005 [1] η^2=0.0752 n=135
Total PRI	F=0.80, p=0.56, η^2=0.0114 n=139	F=0.58, p=0.81, η^2=0.0146 n=117	F=1.98, p=0.055, η^2=0.0377 n=132
Intensity of current LBP	F=1.02, p=0.38, η^2=0.0059 n=114	F=1.96, p=0.44, η^2=0.0111 n=90	F=2.33, p=0.04 [1] η^2=0.0294 n=107
Intensity of LBP over last 1 month	F=0.59, p=0.062 η^2=0.0027 n=112	F=0.80, p=0.542 η^2=0.0063 n=91	F=1.76, p=0.12, η^2=0.0178 n=105
Intensity of LBP over last 3 months	F=0.32, p=0.80, η^2=0.0015 n=111	F=1.40, p=0.23, η^2=0.0111 n=90	F=3.24, p=0.01 [1] η^2=0.0285 n=104
Evaluative PPI of LBP	F=0.83, p=0.54, η^2=0.0041 n=134	F=1.40, p=0.19, η^2=0.011 n=111	F=1.48, p=0.17, η^2=0.0132 n=126

[1]not significant post Bonferroni correction.
Abbreviations: PRI, Pain Rating Index; S-PRI, Sensory-PRI; A-PRI, Affective-PRI; LBP, Low Back Pain; PPI, Present Pain Intensity.
Statistical test: F, Two-way ANOVA.

It has been hypothesised (hypotheses 8 and 9) that:

Hypothesis 0 (null): In people with iSCI there is no significant correlation between the quality (sensory, affective or total PRI) of LBP and pain or LBP onset post iSCI for each national group.

Hypothesis 8a: In people with iSCI there is a significant correlation between the sensory dimension of quality of LBP and pain or LBP onset post iSCI for each national group.

Hypothesis 8b: In people with iSCI there is a significant correlation between the affective dimension of quality of LBP and pain or LBP onset post iSCI for each national group.

Hypothesis 8c: In people with iSCI there is a significant correlation between the total PRI of LBP and pain or LBP onset post iSCI for each national group.

Hypothesis 0 (null): In people with iSCI there is no significant correlation between the intensity of LBP (current, over last 1, last 3 month or evaluative PPI) and pain or LBP onset post iSCI for each national group.

Hypothesis 9a: In people with iSCI there is a significant correlation between intensity of current LBP and pain or LBP onset for each national group.

Hypothesis 9b: In people with iSCI there is a significant correlation between intensity of LBP over the last 1 month and pain or LBP onset for each national group.

Hypothesis 9c: In people with iSCI there is a significant correlation between intensity of LBP over last 3 months and pain or LBP onset for each national group.

Hypothesis 9d: In people with iSCI there is a significant correlation between the evaluative overall LBP intensity and pain or LBP onset for each national group.

Neither earlier pain or LBP onset correlated significantly with the quality of LBP within the USA and Greek groups the strength of the correlations were moderately strong and negative (Table 9.2.10). The correlation between LBP onset post iSC and LBP intensity had the same negative direction and was significant within the USA group where the strength of the relation was slightly stronger than the pain onset for this group (Table 9.2.10).

Table 9.2.10: Correlations between pain or LBP onset and quality or intensity of LBP within each national group

	Pain onset			LBP onset		
	USA	**UK**	**Greece**	**USA**	**UK**	**Greece**
S-PRI	ρ=-0.23 p=0.03[1] n=79	ρ=0.09 p=0.59 n=37	ρ=-0.14 p=0.42 n=31	ρ=-0.33 p=0.005[1] n=71	ρ=-0.01 p=0.95 n=34	ρ=-0.27 p=0.14 n=30
A-PRI	ρ=-0.28 p≤0.01[1] n=79	ρ=0.11 p=0.49 n=37	ρ=-0.46 p=0.009[1] n=31	ρ=-0.30 p≤0.01[1] n=71	ρ=0.07 p=0.68 n=34	ρ=-0.48 p=0.007[1] n=30
Total PRI	ρ=-0.24 p=0.03[1] n=78	ρ=0.10 p=0.54 n=35	ρ=-0.23 p=0.21 n=31	ρ=-0.33 p=0.005[1] n=70	ρ=-0.01 p=0.90 n=32	ρ=-0.37 p=0.44 n=30
Intensity of current LBP	ρ=-0.18 p=0.09 n=81	ρ=0.01 p=0.93 n=35	ρ=-0.5 p=0.66 n=3	ρ=-0.42 **p≤0.001***** n=73	ρ=-0.02 p=0.90 n=32	n/a
Intensity of LBP over last 1 month	ρ=-0.16 p=0.15 n=81	ρ=0.09 p=0.61 n=33	ρ=-0.5 p=0.66 n=3	ρ=-0.41 **p≤0.001***** n=73	ρ=-0.10 p=0.57 n=30	n/a
Intensity of LBP over last 3 months	ρ=-0.26 p=0.02[1] n=80	ρ=0.15 p=0.38 n=33	ρ=-0.50 p=0.66 n=3	ρ=-0.51 **p≤0.001***** n=72	ρ=-0.01 p=0.92 n=30	n/a
Evaluative PPI of LBP	ρ=-0.20 p=0.07 n=74	ρ=0.36 p=0.04[1] n=32	ρ=0.08 p=0.67 n=30	ρ=-0.27 p=0.02[1] n=68	ρ=0.22 p=0.25 n=29	ρ=-0.07 p=0.71 n=29

n/a: Data from the Greek group on the intensity of LBP was only given by three respondents thus will not be examined[37]. Data for the evaluative PPI intensity was used normally, [1]not significant post Bonferroni correction; ***Significant at p≤0.001 level, **in bold**: significant following application of the Bonferroni correction.
Abbreviations: PRI, Pain Rating Index; LBP, Low Back Pain; PPI, Present Pain Intensity.
Statistical tests: ρ, Spearman's rank correlation rho.

9.2.10 LBP quality and intensity across nations; relation to body chart

It was found earlier for the pooled group that as the number of painful areas on the body increased, the quality of LBP became worse and LBP intensity increased (Chapter 6, Section 6.2.10). These correlations were not significant when examining the groups from the three countries. The only exception was for the US group where there was a

[37] For an explanation of why there are only three respondents from Greece answering this question refer back to Chapter 6, Section 6.2.7.

correlation between the number of areas with pain and evaluative intensity of LBP. Despite correlations not being statistically significant they were often of moderate strength especially for the quality of LBP (Appendix 9: Table 9.b.8.3).

Part 3; EQ-5D: Pain and quality of life within and across nations

9.3.1 Introduction

So far this chapter has examined the demographic profiles of the respondents per country and their pain and LBP experiences. This part of the chapter will present the QoL for each group per individual country and will examine how QoL relates to the experience of pain and LBP.

9.3.2 Bonferroni Correction

The main variables of interest included in the analysis here were two; 1) the EQ-5D index, and 2) the EQ-VAS. Both were involved in 26 individual tests thus the α-level of significance for Bonferroni correction was set at p≤0.002 (Appendix 9; Table 9.c.1.1).

9.3.3 QoL across nations; general results

Looking at people from each country they all reported some problems with the EQ-5D dimensions[38]. People from the USA seemed to have less "self-care" problems and were less anxious/depressed compared to those from the other countries. At the same time, more people from the UK reported severe levels of pain (Figure 9.3.1). Scoring of the EQ-5D dimensions confirmed that the differences between the groups from the three countries were not great as no statistically significant differences were found (p=0.75, F=0.20, One-way ANOVA, n=198). However, a significant difference was found in the perception of self-rated health (p≤0.001, F=9.73, One-way ANOVA, n=198) and Bonferroni post hoc showed that people from Greece reported significantly worse

[38] For an explanation of the characteristics of the EQ-5D measure see Chapters 5 and 7.

perceived health status (EQ-VAS) than those from the USA (p≤0.001, Bonferroni Post Hoc I-J=16.89, 95% CI 7.4, 26.3, Table 9.3.1).

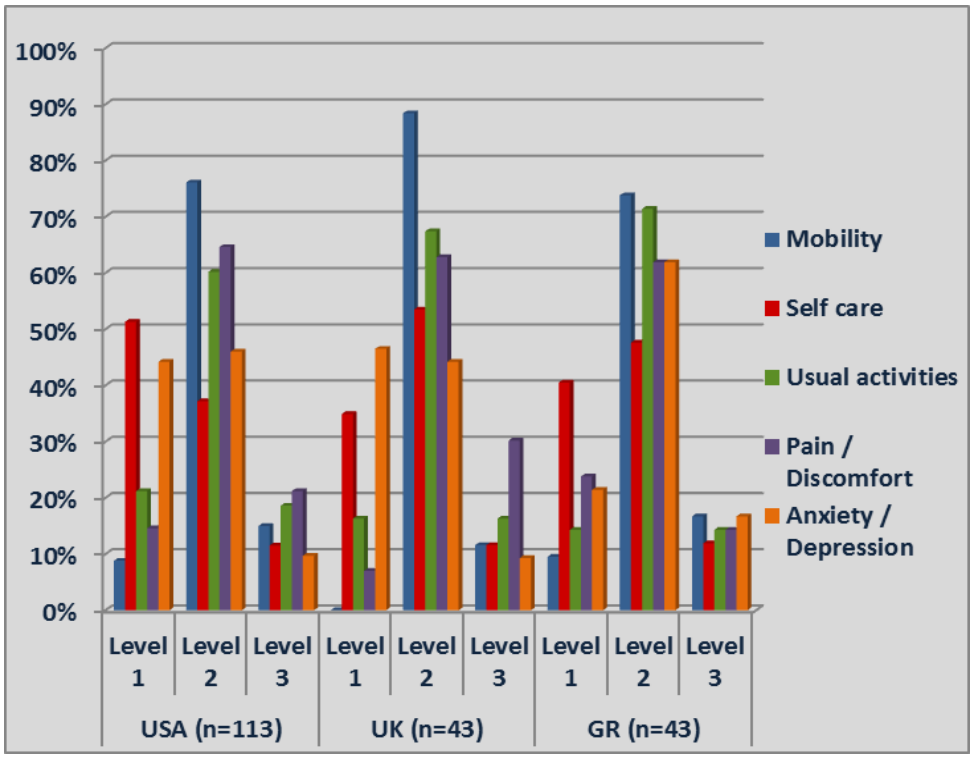

Figure 9.3.1: Percentage of people, within each national group, reporting their health status dimensions

Table 9.3.1: Mean QoL of people within each national group. Differences in the mean QoL between national groups

	USA	UK	GR	Statistical Tests
EQ-5D Index mean±SD	0.37±0.34	0.33±0.35	0.39±0.37	F=0.20 p=0.75 n=198
EQ-VAS mean±SD	68.2±21.4	60.4±24.5	51.3±18.8	F=9.73 **p≤0.001*** ** USA-GR (I-J) 16.89, **p≤0.001*** **, 95%CI 7.4, 26.3, n=198

***Significant at p≤0.001 level, **in bold:** significant following application of the Bonferroni correction or post hoc.
Abbreviations: EQ-5D, Quality of Life, EQ-VAS, Quality of Life Visual Analogue Scale.
Statistical test: F, One-way ANOVA.

9.3.4 QoL across nations; relation to pain, MSKP and LBP

People with pain, MSKP and LBP from all three countries replied similarly on the EQ-5D dimensions with most reporting some problems. Irrespective of the type of pain, people from the USA seemed to have fewer problems with "self-care" (Figure 9.3.2, 9.3.3, 9.3.4). One thing noted throughout the groups when people did not have pain, MSKP or LBP was that anxiety/depression levels dropped (Appendix 9: Figures 9.c.2.1-9.c.2.3).

In Chapter 5 it was found that among the total group, people without pain, MSKP or LBP had a better, though not statistically significant, QoL. Here the interaction effect between the country of residence and the presence of the categories of pain of interest on QoL was examined but no significant results were found (Table 9.3.2).

To investigate the relation of the presence of the pain categories with QoL (hypothesis 2) within each national group the following was hypothesised:

Hypothesis 0 (null): In people with iSCI there is no significant difference in QoL (EQ-5D index or EQ-VAS) between people with pain, LBP or MSKP and those without for each national group.

Hypothesis 2a: In people with iSCI there is a significant difference in QoL (EQ-5D index or EQ-VAS) between people with pain and those without for each national group.

Hypothesis 2b: In people with iSCI there is a significant difference in QoL (EQ-5D index or EQ-VAS) between people with MSKP and those without for each national group.

Hypothesis 2c: In people with iSCI there is a significant difference in QoL (EQ-5D index or EQ-VAS) between people with LBP and those without for each national group.

The same significant differences, as per the pooled group, were confirmed within the USA group and the Greek group but not for the UK group (Table 9.3.3; Appendix 9: Table 9.c.2.4). Earlier in Chapter 7, among the pooled group, people with MSKP or LBP perceived their self-rated health as worse than those without. Examining the data cross-nationally, it was found that the presence of any of the pain categories did not

affect classification or perception of health status for the Greeks or people from the UK, however the effect sizes were, on occasion, moderate implying a practical significance (Table 9.3.3). The presence of the pain categories had a stronger impact on the health status for people from the USA, particularly those with LBP who classified and perceived their health status as worse that those without LBP (Table 9.3.3).

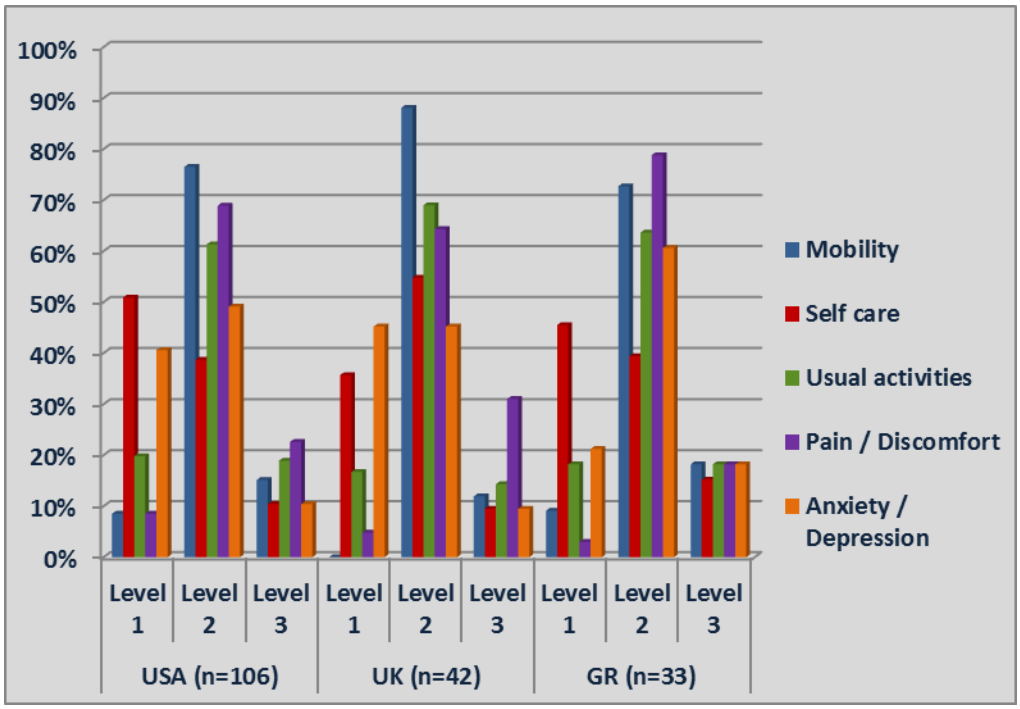

Figure 9.3.2: Percentage of people with pain in general, within each national group, reporting their health status dimensions

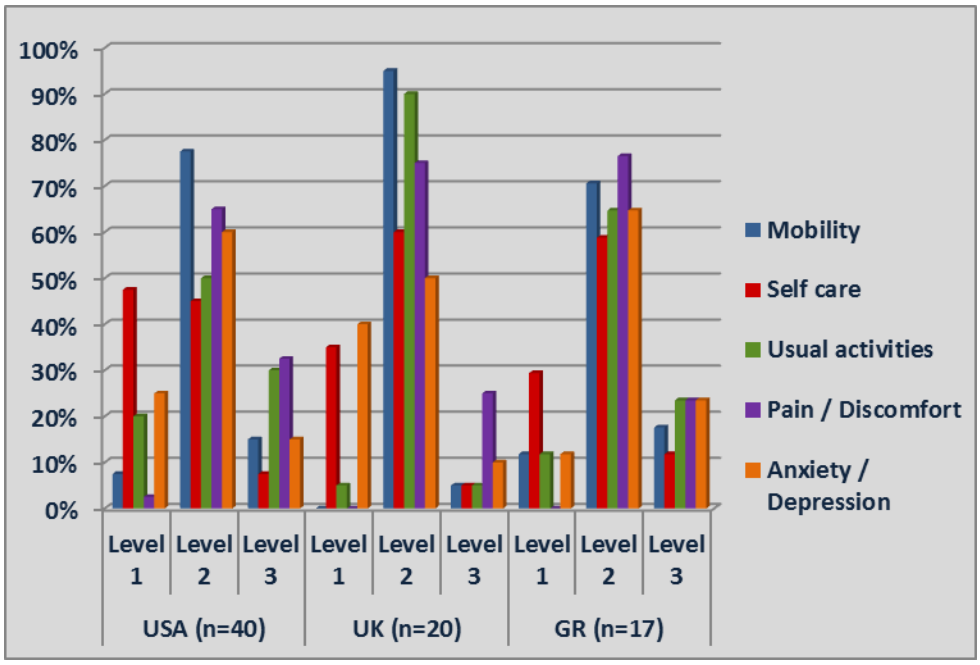

Figure 9.3.3: Percentage of people with MSKP, within each national group, reporting their health status dimensions

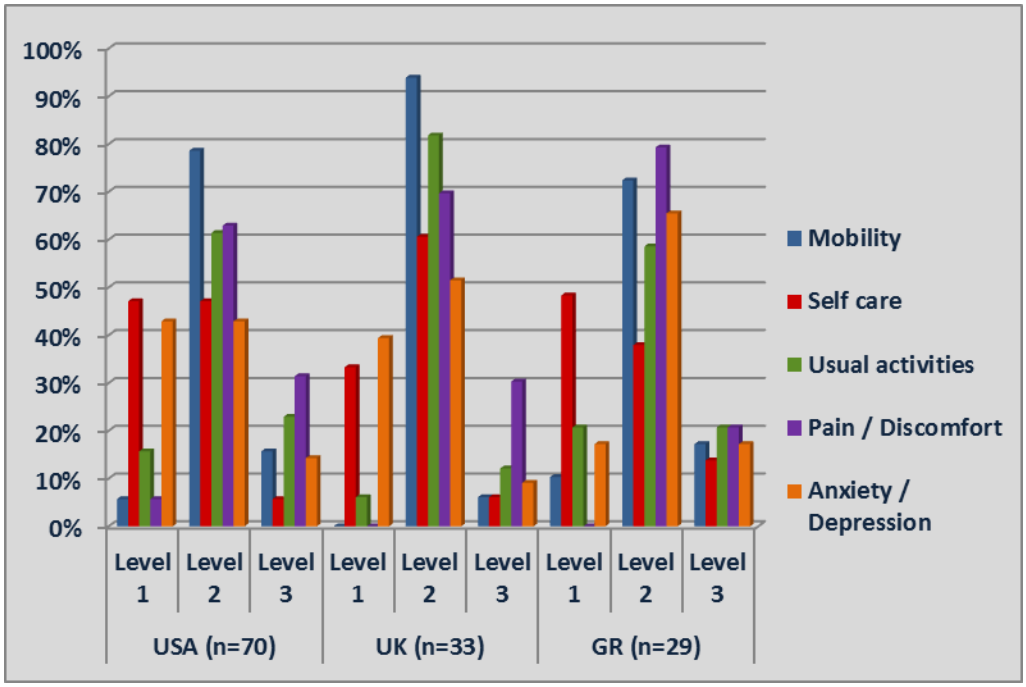

Figure 9.3.4: Percentage of people with LBP, within each natinal group, reporting their health status dimensions

Table 9.3.2: Interaction effects of country of residence and presence of pain/MSKP/LBP on health status

	Effect of presence of pain *country on DV	Effect of presence of MSKP *country on DV	Effect of presence of LBP *country on DV
EQ-5D index	F=0.42, p=0.065 η^2=0.0020 n=198	F=3.31, p=0.03[1] η^2=0.0161 n=193	F=2.09, p=0.12 η^2=0.0101 n=191
EQ-VAS	F=1.93, p=0.14 η^2=0.0019 n=198	F=1.76, p=0.17 η^2=0.0018 n=193	F=0.63, p=0.52 η^2=0.00064 n=191

[1]not significant post Bonferroni correction;
Abbreviations: EQ-5D, Quality of Life, EQ-VAS, Quality of Life Visual Analogue Scale.
Statistical test: F, Two-way ANOVA.

Table 9.3.3: Comparisons within countries for EQ-5D Index or EQ-VAS and pain categories (between people with and without pain categories)

EQ-5D	USA	UK	GR
Pain in general	U=148, n=113 ES: r=-0.24 p=0.008[1]	U=18, n=43 ES: r=-0.03 p=0.80	U=81,n=42 ES: r=-0.31 p=0.03[1]
Current LBP	t=3.31, df105, n=107 ES: d=0.66 **p≤0.001***** 95%CI 0.08, 0.3	U=162.5, n=43 ES: r=-0.01 p=0.92	U=126, n=41 ES: r=-0.21 p=0.16
MSKP	t=2.55, df109, n=111, ES: d=0.48 p≤0.01[1] 95%CI 0.03, 0.3	t=-1.24, df40, n=42, ES: d=0.28 p=0.21 95%CI -0.3, 0.08	U=91, n=40 ES: r=-0.31 p≤0.01[1]
EQ-VAS	**USA**	**UK**	**GR**
Pain in general	U=212,n=113 ES: r=-0.17 p=0.058	U=0.0, n=43 ES: r=-0.25 p=0.08	U=115, n=41 ES: r=-0.02 p=0.057
Current LBP	t=3.81, df105, n=107, ES: d=0.81 **p≤0.001***** 95%CI 7.4, 23.6	t=1.87, df41, n=43, ES: d=0.64 p=0.06 95%CI -1.24, 33.4	t=1.76, df38, n=41, ES: d=0.36 p=0.008[1] 95%CI -1.4, 21.1
MSKP	t=2.60, df109, n=111, ES: d=0.51 p≤0.01[1] 95%CI 2.5, 19.0	U=52, n=42 ES: r=-0.01 p=0.003[1]	t=1.03, df39, n=40, ES: d=0.36 p=0.30 95%CI -6.3, 19.6

[1]not significant post Bonferroni correction; ***Significant at p≤0.001 level,
in bold: significant following application of the Bonferroni correction;
Abbreviations: LBP, Low Back Pain; MSKP, Musculoskeletal Pain; EQ-5D, Quality of Life; EQ-VAS, Quality of Life Visual Analogue Scale.
Statistical tests: U, Mann-Whitney U test; t, Independent t-test.

9.3.5 QoL across nations; relation to demographic profile characteristics

9.3.5.1 Gender across nations

The interaction effect of the country of residence and gender was not significant on the QoL which means that where people lived in combination with whether they were males or females did not predict how their QoL would be. Between the three national groups men from the USA seemed to be less anxious than all other respondents. On the other hand, women from Greece reported the most severe anxiety/depression problems despite their pain problems not being as severe as females or males from the other countries. Problems with mobility were similar across all countries for men and women (Figures 9.3.5, 9.3.6; Appendix 9: Table 9.c.3.1). Scoring of the EQ-D5 dimensions confirmed the similarities of the sexes within the country groups and therefore the original finding, when using the pooled group, of no gender differences in the EQ-5D index was maintained (Appendix: Table 9.c.3.6).

A difference in MSKP between males and females was found pre-application of the Bonferroni correction in Chapter 6. Some further analysis on MSKP and QoL by gender was conducted and is presented at Appendix 9: Table 9.c.3.2 as it was not part of the main analysis.

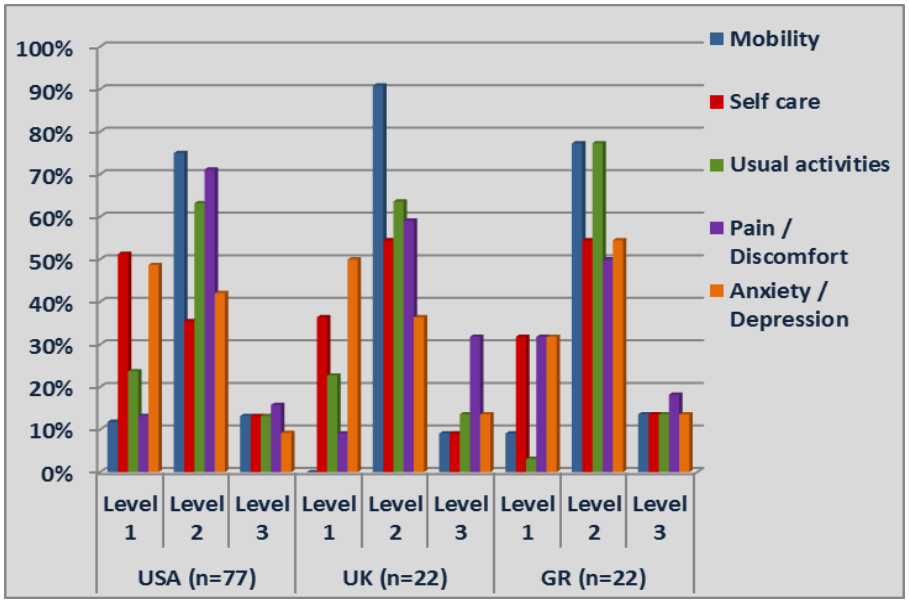

Figure 9.3.5: Percentage of males, within each national group, reporting their health status dimensions

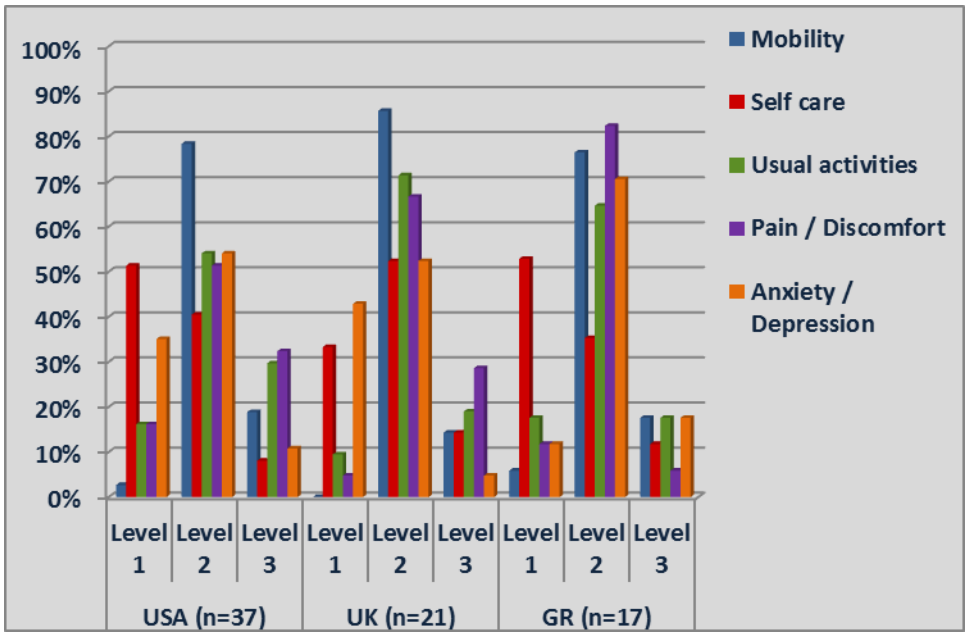

Figure 9.3.6: Percentage of females, within each national groups, reporting their health status dimensions

9.3.5.2 Cause of injury across nations

The country of residence in combination with the cause of injury could not predict the health status of the participants as no significant interaction effect was found either on the *classification* of health state or the *perception* of self-reported heath; interaction effect between cause of injury and country of residence on the EQ-5D index: p=0.66, ($F=0.41$, $\eta^2=0.0033$, two-way ANOVA, n=131); interaction effect between the cause of injury and the country of residence on the EQ-VAS: $p \leq 0.01$, ($F=4.57$, $\eta^2=0.0081$, two-way ANOVA, n=131). People with traumatic injuries from the different countries reported fairly similarly on the EQ-5D dimensions. However, people with a traumatic injury from the UK seemed to suffer more with pain/discomfort than people in the other countries. Conversely, among people with a non-traumatic injury the least anxious/depressed came from the UK, despite reporting the more severe levels of pain/discomfort (Figures 9.3.7, 9.3.8; Appendix 9: Table 9.c.3.3). Scoring of the EQ-5D dimensions within each group confirmed the similarities between people with traumatic and non-traumatic injury as no significant differences were found (Appendix 9: Table 9.c.3.6). In the case of perceived self-rated health, within the USA group

people with non-traumatic injuries reported a significantly lower mean than those with a traumatic injury (p≤0.001, t=4.25, 95%CI 10.1, 27.6, independent t-test).

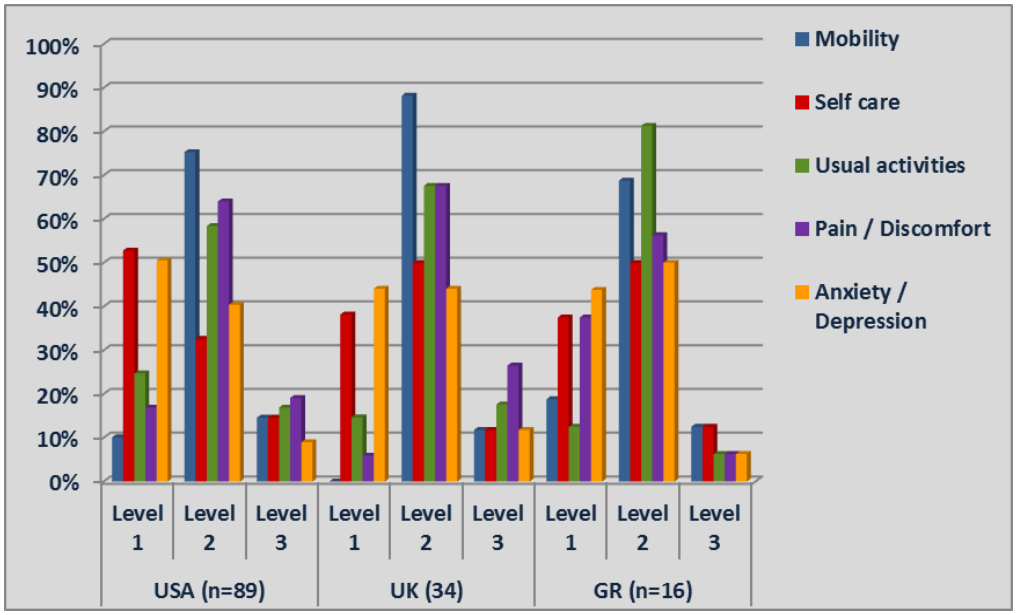

Figure 9.3.7: Percentage of people with traumatic injury, within each national groups, reporting their health status dimensions

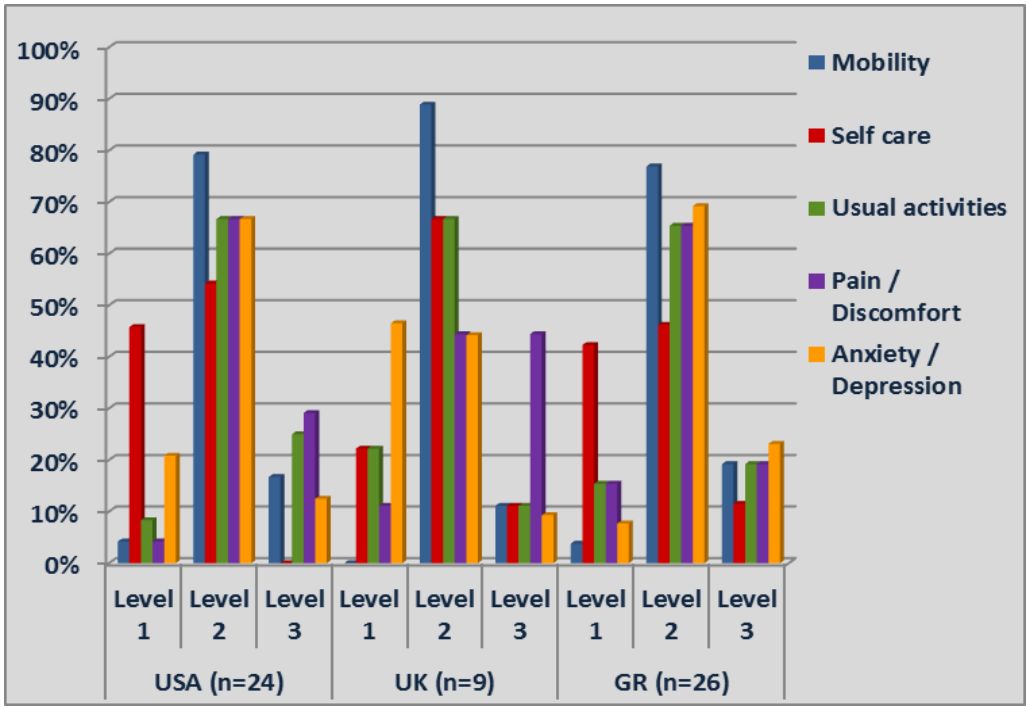

Figure 9.3.8: Percentage of people with non-traumatic injury, within each national group, reporting their health status dimensions

9.3.5.3 Level of injury across nations

In earlier analysis of the pooled data (Chapter 7, Section 7.6), it was found that people with tetraplegia perceived their health status as better than people with paraplegia. Here, the country of residence in combination with the level of injury did not predict the QoL as no interaction effects were significant; interaction effect between level of injury and country of residence on the EQ-5D index: p=0.11, (F=1.91, η^2=0.0300, two-way ANOVA, n=131); interaction effect between level of injury and country of residence on the EQ-VAS: p=0.16, (F=1.64, η^2=0.0059, two-way ANOVA, n=131). Between the groups from the three countries, those with tetraplegia from the UK seemed to be less anxious/depressed despite reporting the most severe levels of pain/discomfort. People with paraplegia were, within all groups, better with their "self-care" and their "usual activities" compared to people with tetraplegia (Figures 9.3.9, 9.3.10; Appendix 9: Table 9.c.3.4). Scoring of the EQ-5D dimensions showed that people with tetraplegia and paraplegia did not differ significantly within each group from country to country (Appendix 9: Tables 9.c.3.5). People with tetraplegia perceived their self-rated health as better compared to people with paraplegia, similar to the pooled group, but the difference was not significant which could be due to having smaller sized groups (Appendix 9: Table 9.c.3.6).

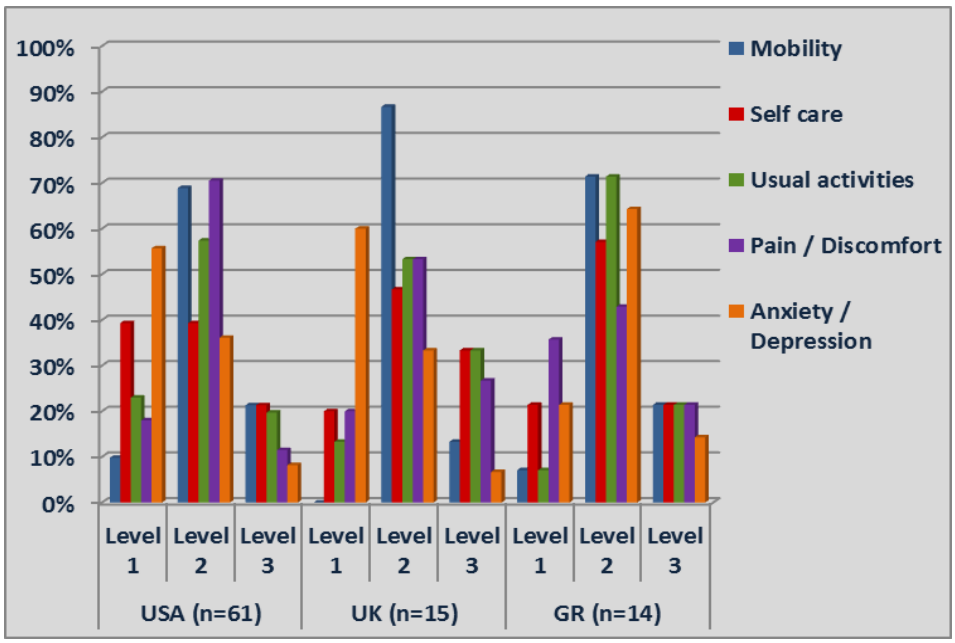

Figure 9.3.9: Percentage of people with tetraplegia injury, within each national group, reporting their health status dimensions

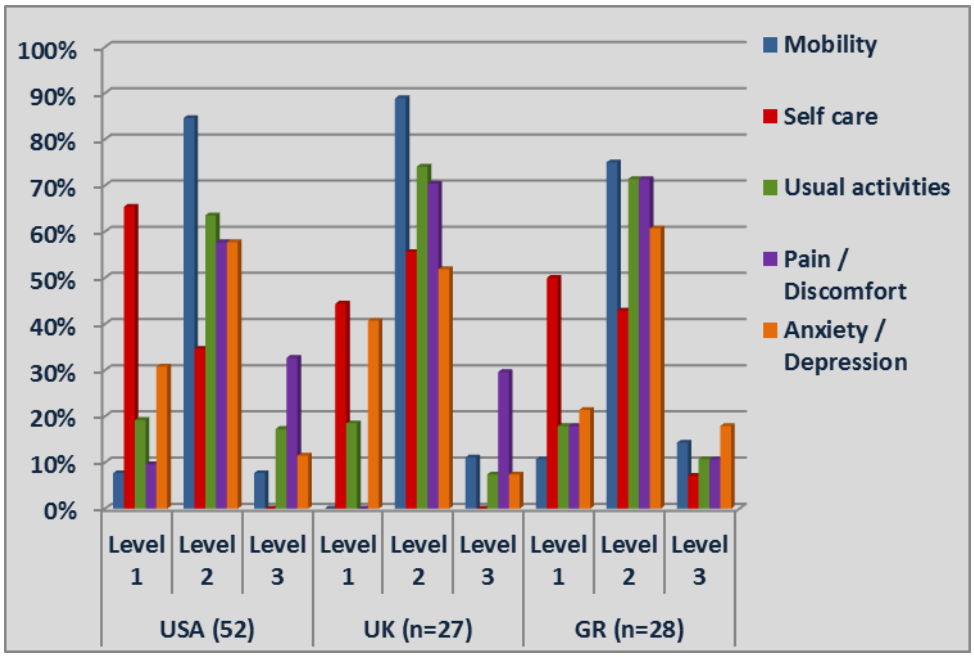

Figure 9.3.10: Percentage of people with paraplegia injury, within each national group, reporting their health status dimensions

9.3.5.4 Age across nations

Originally, in the pooled group (Chapter 7, Section 7.6), it was found that age did not correlate with the EQ-5D index and the direction of the correlation was positive but very weak showing that increasing age slightly correlated with worse health status classification. Within each separate group from the three countries the correlation remained the same in terms of not being significant, the direction of the correlations was weak and positive for the USA and Greece but negative for the UK (Appendix 9: Table 9.c.3.7, Figure 9.c.3.1, Table 9.c.3.8). The country of residence in combination with age could not predict the EQ-5D index as the interaction effect was not significant (Table 9.3.3). Though age did not significantly correlate with *perception* of self-rated health within any group, the direction of the relation indicated that increasing age negatively related with health perception for people from all nations (Appendix 9: Table 9.c.3.7). However, the interaction effect of the country of residence and age on self-rated health perception was significant ($p \leq 0.001$, Wald $\chi^2=33.84$, df3, n=190). In

particular, as age increases, people from the USA, the UK or Greece are more likely to *perceive* their self-rated health as deteriorating (Table 9.3.3).

Earlier it was found that time since injury does not correlate significantly with QoL, but people *classified* their health status as slightly worse and *perceived* it as better (Chapter 7, Section 7.6). When time since injury was examined within each group from the participating countries, those from the UK with longer time since injury seemed to report severe problems with "self-care" and "pain/discomfort". Those with less time since injury reported severe problems with "anxiety/depression" but for the Greeks, those with the longest time since injury reported more problems with "anxiety/depression" (Appendix 9: Figure 9.c.3.2, Table 9.c.3.10). Those from the USA with a short time since injury reported severe problems with their usual activities. However, this changed as time since injury increases and more people reported no problems with usual activities. Scoring of the EQ-5D index did not reveal any significant correlation between time since injury and classification of health status (Appendix 9: Table 9.c.3.9). In addition, the interaction effect between the country of residence and time since injury was not significant on the health status classification (Table 9.3.3). The perception of the respondents about their self-rated health decreased with the passing of time for Greeks and people from the UK but increased for people from the USA. However, none was significant (Appendix 9: Table 9.c.3.9). But the country of residence in combination with the time since injury affected the self-rated health perception ($p \leq 0.001$, Wald $\chi^2=33.84$, df3, n=190). In particular, as time since injury increased, people from the USA were more likely to perceive their self-rated health as better while Greeks were more likely to perceive it as worse (Table 9.3.3).

Table 9.3.3: Interaction effects of residence and age or time since injury on health status

	Effect of age or time since injury and country on EQ-5D	Effect of age or time since injury and country on EQ-VAS
Age	p=0.65 df3, n=190 Wald χ^2=1.60, Likelihood ratio χ^2=1.60 p=0.65	**p≤0.001*****, df3, n=190 Wald χ^2=33.84, Likelihood ratio χ^2=31.14, **p≤0.001***** USA*age: **p=0.005****, b=-0.38, SE=0.13, Wald χ^2=7.8, df3, 95% CI for Wald -0.66, -0.11 UK*age: **p=0.001*****, b=-0.53, SE=0.13, Wald χ^2=15.25, df3, 95% CI for Wald -0.53, -0.11 Greece*age: **p≤0.001*****, b=-0.52, SE=0.10, Wald χ^2=24.49, df3, 95% CI for Wald -0.72, -0.31
Time since injury	p=0.65, df3, n=197 Wald χ^2=1.611, Likelihood ratio χ^2=1.61, p=0.65	**p≤0.001*****, df3, n=197 Wald χ^2=21.5, Likelihood ratio χ^2=20.41, **p≤0.001***** USA*age: **p=0.02***, b=0.39, SE=0.16, Wald χ^2=5.44, df3, 95% CI for Wald -0.06, -0.72 Greece*age: **p=0.002****, b=-0.83, SE=0.27, Wald χ^2=9.46, df3, 95% CI for Wald -1.37, -0.30

¥The Greek group was excluded due to insufficient data; **Significant at p≤0.01 level, ***Significant at p≤0.001 level, **in bold:** significant following application of the Bonferroni correction;
Abbreviations: MSKP, Musculoskeletal Pain; LBP, Low Back Pain; SE, Standard Error;
Statistical tests: χ^2, Likelihood ratio Chi-square; Wald test chi-square distribution;

9.3.5.5 Marital status across nations

In Chapter 7, Section 7.6 the variables of marital status, education and employment were examined for their possible impact on QoL as in the literature they have been found to have an effect on QoL (Chapter 2). For the pooled group no difference was found in the QoL between people who were married or in a relationship and those who were single/divorced/widowed. Similarly, they did not perceive their self-rated health differently. The interaction effect between the country of residence in combination with marital status did not predict QoL; effect on the EQ-5D index: p=0.51, (F=0.66, η^2=0.0033, two-way ANOVA, n=194); effect on the EQ-VAS: p=0.55,

(F=0.57, η^2=6.073, two-way ANOVA, n=194). Within the groups from each country, people within and without a relationship replied very similarly on all five health status dimensions and no major differences were noticed (Appendix 9: Table 9.c.3.11). Indeed, scoring of the EQ-5D dimensions confirmed that within each group from the three countries people in or not in a relationship did not differ on their QoL reports either on the classification of their health status or on their self-rated perception of their health (Appendix 9: Table 9.c.3.14).

9.3.5.6 Level of education across nations

Previously examining the pooled group it was found that people with better education differed in their QoL compared to people with lower levels of education (Chapter 7, Section 7.6). The interaction effect between the level of education and country of residence was found to be significant but did not to pass the Bonferroni α-level of correction; effect on EQ-5D index: p=0.006, (F=3.16, η^2=0.0434, Two-way ANOVA, n=196); effect on the EQ-VAS: p=0.04, (F=2.23, η^2=0.00694, Two-way ANOVA, n=196. Within each group from the three countries but also between the countries, those with higher levels of education did not seem to differ on the five health status dimensions from those with lower levels of education. However, for the UK group, it seemed that less people with increased severity of mobility would get a good level of education compared to people from the USA (Appendix 9: Table 9.c.3.12). Scoring of the EQ-5D dimensions showed that people with different education levels did not differ in their EQ-5D index either in their health status classification or their perception within any national group. Education level did not significantly affect perception of self-rated health for people from any of the three groups (Appendix 9: Table 9.c.3.15).

9.3.5.7 Employment across nations

Earlier, in the analysis of the pooled group, it was found that employed people classified and perceived their health status as significantly better than unemployed and

retired people (Chapter 7, Section 7.6). The country in which respondents lived in combination with their employment status did not affect their QoL; interaction effect on EQ-5D index: p=0.78, (F=0.43, η^2=0.0040, Two-way ANOVA, n=197); interaction effect on EQ-VAS: p=0.17, (F=0.16, η^2=0.0031, Two-way ANOVA, n=197). Within all three groups from the individual countries, people employed, unemployed and retired reported some problems with mobility. It was noticed that within the UK group all people with severe mobility issues were unemployed, which was not the case for the other two countries. In the USA group, more people who were employed reported not having any problems with "anxiety/depression" (Appendix 9: Table 9.c.3.13). Scoring of the EQ-5D dimensions showed that though people in employment scored better on their QoL, the differences were not significant. When people reported on how they perceived their self-rated health no significant differences were found between people employed, unemployed or retired. However, employed Greeks seem to have a much better perceived self-rated health than retired people.

9.3.6 QoL across nations; relation to pain/LBP days, free weeks, onset

The earlier analysis of the pooled group showed that the more LBP days felt in the month the worse the QoL (Chapter 7, Section 7.7). Though there were differences in the EQ-5D dimensions within the groups from the three countries, as a rule those who had LBP for more days reported more severe problems with the dimensions (Appendix 9: Table 9.c.4.1). Another earlier finding for the pooled group was that as the frequency of LBP-free weeks decreased so did health status (Chapter 7, Section 7.7). The country of residence in combination with LBP days did not affect health status; interaction effect between LBP days felt per month and country of residence on the EQ-5D index: p=0.99, (F=0.10, η^2=0.0021, two-way ANOVA, n=139); on EQ-VAS: p=0.40, (F=1.03, η^2=0.0051, two-way ANOVA, n=127). Similarly, the interaction effect between the number of pain days felt per month and country on QoL was not significant; on EQ-5D index: p=0.71, (F=0.61, η^2=0.0101, two-way ANOVA, n=177); on EQ-VAS: p=0.99, (F=0.42, η^2=0.0033, two-way ANOVA, n=177). Within each national group none of the

correlations were statistically significant but they were all negative and moderate to strong particularly in relation to the perception of health (Table 9.3.4). The correlation between pain days and health status gave similar findings (Table 9.3.4).

The frequency of pain (in general) breaks (Appendix 9: Table 9.c.4.2) also had a moderate to strong correlation with QoL and, in the case of the UK group, it was highly statistically significant for perception of self-rated health ($p \leq 0.001$, $\rho = -0.53$, Spearman's ρ, n=40) (Table 9.3.4). The country of residence in combination with the frequency of the LBP-free weeks did not impact on QoL; interaction effect between LBP-free weeks and country of residence on the EQ-5D: p=0.54, ($F=0.88$, $\eta^2=0.0355$, two-way ANOVA, n=116); interaction on perceived self-rated health: p=0.54, ($F=0.88$, $\eta^2=0.0348$, two-way ANOVA, n=116). The same was found for the pain-free week; interaction between pain-free weeks and country of residence on the EQ-5D: p=0.51, ($F=0.92$, $\eta^2=0.026$, two-way ANOVA, n=166); interaction on EQ-VAS: p=0.52, ($F=0.84$, $\eta^2=0.0051$, two-way ANOVA, n=166) (see also Appendix 9: Tables 9.c.4.3 and 9.c.4.4.

Finally, earlier analysis done as part of the second hypothesis theme showed that the earlier the LBP onset after iSCI, the worse the health status *classification* and the self-rated health *perception*. Here no significant interaction effect was found between LBP onset and country of residence on the EQ-5D index: p=0.69, ($F=0.69$, $\eta^2=0.0225$, two-way ANOVA, n=131); or EQ-VAS: p=0.46, ($F=0.96$, $\eta^2=0.0071$, two-way ANOVA, n=131). There was also no significant interaction effect between pain onset and country of residence on the EQ-5D index: p=0.64, ($F=0.74$, $\eta^2=0.0037$, two-way ANOVA, n=171); or the EQ-VAS: p=0.35, ($F=1.1$, $\eta^2=0.057$, two-way ANOVA, n=171) (see also Appendix 9: Tables 9.c.4.5-9.c.4.7).

Hypothesis five has now been made as:

Hypothesis 0 (null): In people with iSCI there is no significant correlation between QoL (EQ-5D index or EQ-VAS) and the onset of pain or LBP post iSCI for each national group.

Hypothesis 5a: In people with iSCI there is a significant correlation between QoL (EQ-5D index or EQ-VAS) and the onset of pain post iSCI for each national group.

Hypothesis 5b: In people with iSCI there is a significant correlation between QoL (EQ-5D index or EQ-VAS) and the onset of LBP post iSCI for each national group.

Examining each country group separately no significant correlations either between pain or LBP onset post iSCI and the EQ-5D index were found and the strength of the correlations were small. Relationships were stronger between pain or LBP onset, post iSCI, and perceived self-rated health within all groups, and for the USA group it reached a significant level in the case of LBP onset (Table 9.3.4).

Table 9.3.4: Correlations between pain or LBP days or free weeks or onset (post iSCI) and health status within each national group

EQ-5D Index	USA	UK	GR
Pain onset post iSCI	ρ=0.01, n=99 p=0.90, 95%CI -0.18, 0.20	ρ=-0.02, n=40 p=0.87, 95%CI -0.29, 0.32	ρ=0.17, n=32 p=0.87, 95%CI -0.17, 0.49
LBP onset post iSCI	ρ=0.15, n=71 p=0.18, 95%CI -0.08, 0.37	ρ=0.18, n=31 p=0.31, 95%CI -0.20, 0.46	ρ=0.25, n=29 p=0.17, 95%CI -0.12, 0.55
Pain days	ρ=-0.27 p=0.05[1], n=104	ρ=-0.30 p=0.04[1], n=42	ρ=-0.16 p=0.24, n=31
LBP days	ρ=-0.30 p=0.007[1], n=77	ρ=-0.19 p=0.28, n=32	ρ=-0.25 p=0.17, n=30
Pain free weeks	ρ=-0.28 p=0.005[1], n=95	ρ=-0.39 p≤0.01[1], n=40	ρ=-0.36 p=0.04[1], n=31
LBP free weeks	ρ=-0.18 p=0.15, n=60	ρ=-0.22 p=0.25, n=27	ρ=-0.42 p=0.02[1], n=29
EQ-VAS	**USA**	**UK**	**GR**
Pain onset post iSCI	ρ=0.27, n=99 p=0.007[1], 95%CI 0.27, 0.43	ρ=0.26, n=40 p=0.10, 95%CI -0.24, 0.61	ρ=0.15, n=32 p=0.40, 95%CI -0.20, 0.46
LBP onset post iSCI	ρ=0.38, n=71 **p≤0.001***,** 95%CI 0.00, 0.68	ρ=-0.09, n=31 p=0.59, 95%CI -0.84, 0.77	ρ=0.16, n=29 p=0.38, 95%CI -0.21, 0.49
Pain days	ρ=-0.23 p≤0.01[1], n=104	ρ=-0.49 **p≤0.001*****, n=42	ρ=-0.52 **p=0.002****, n=31
LBP days	ρ=-0.35 **p=0.002****, n=77	ρ=-0.31 p=0.07, n=32	ρ=-0.40 p=0.02[1], n=30
Pain free weeks	ρ=-0.22 p=0.02[1], n=95	ρ=-0.53 **p≤0.001*****, n=40	ρ=-0.33 p=0.07, n=31
LBP free weeks	ρ=-0.31 p≤0.01[1], n=60	ρ=-0.39 p=0.03[1], n=27	ρ=-0.45 p≤0.01[1], n=29

[1]not significant post Bonferroni correction; *Significant at p≤0.05 level, **Significant at p≤0.01 level, ***Significant at p≤0.001 level, **in bold:** significant following application of the Bonferroni correction;
Abbreviations: EQ-5D, Quality of Life, EQ-VAS, Quality of Life Visual Analogue Scale; iSCI, incomplete Spinal Cord Injury; LBP, Low Back Pain.
Statistical tests: ρ, Spearman's rank correlation rho.

9.3.7 QoL across nations; relation to pain extent

Previous analysis (Chapter 7, Section 7.8) found a decrease in the QoL (both EQ-5D and EQ-VAS) when the number of painful areas on the body increased but not significantly. The interaction effect between the number of areas with pain and country of residence on either EQ-5D or EQ-VAS was not significant; on EQ-5D: p=0.19, (F=1.34, η^2=0.0453, two-way ANOVA, n=174); on EQ-VAS: p=0.24, (F=1.27, η^2=0.0093, two-way ANOVA, n=174). Examining each group from the individual countries, it was found that the correlation was significant for the USA group for EQ-5D index: p≤0.001, (r=-0.31, Pearson's correlation, n=101) (Table 9.3.5; Appendix 9: Table 9.c.5.1).

Table 9.3.5: Correlations between the number of areas with pain and EQ-5D or EQ-VAS within each national group

	USA	UK	GR
EQ-5D Index	r=-0.31 **p≤0.001*****, n=101	r=-0.07 p=0.63, n=41	ρ=-0.05 p=0.75, n=32
EQ-VAS	r=-0.28 p=0.004[1], n=101	r=0.03 p=0.83, n=41	r=-0.33 p=0.06, n=32

[1]not significant post Bonferroni correction; ***Significant at p≤0.001 level,
in bold: significant following application of the Bonferroni correction;
Abbreviations: EQ-5D, Quality of Life, EQ-VAS, Quality of Life Visual Analogue Scale.
Statistical tests: r, Pearson's correlation; ρ, Spearman's rank correlation rho.

9.3.8 QoL across nations; relation to quality and intensity of LBP

Part of the third hypothesis theme was to examine the relationship between LBP quality and intensity and QoL, which here was examined within and between the groups from each country. It was noticed that as the quality of LBP became worse so did the level of severity of the health status dimensions. "Anxiety/depression" seemed to increase a lot for the UK group when the affective dimension of LBP became worse. For the same group mobility also became more severe when the total PRI of LBP became worse (Figures 9.3.11-9.3.13).

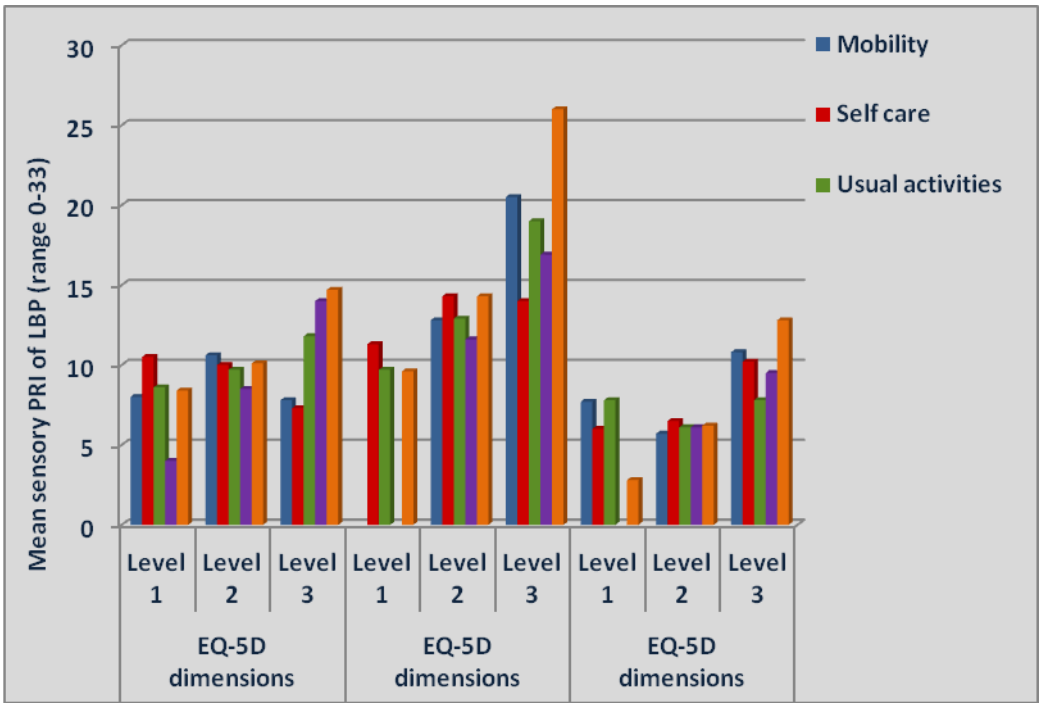

Figure 9.3.11: Mean sensory dimension of LBP reported by people, divided in groups by country, for each level of the EQ-5D dimensions

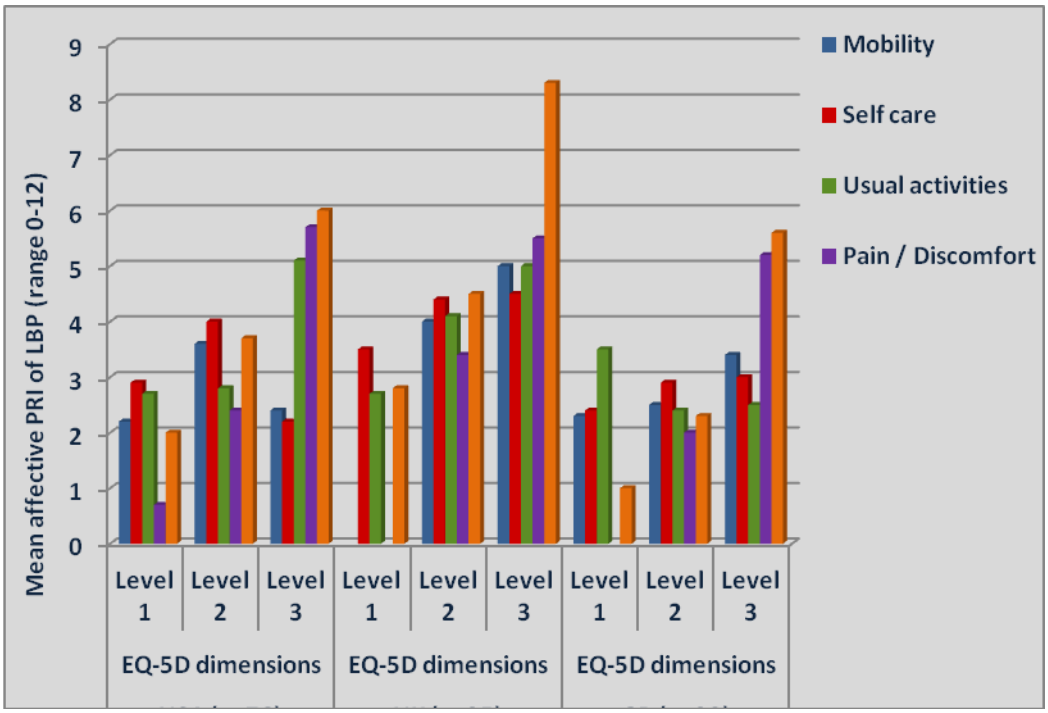

Figure 9.3.12: Mean affective dimension of LBP reported by people, divided in groups by country, for each level of the EQ-5D dimensions

Abbreviations: EQ-5D, Quality of Life; PRI, Present Rating Index

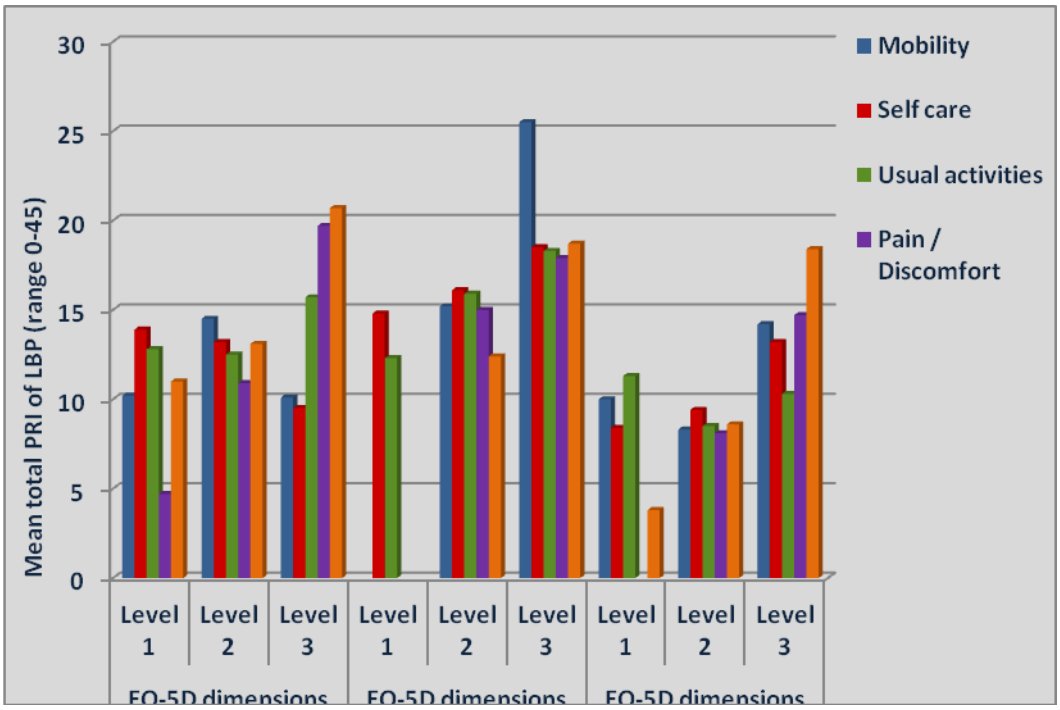

Figure 9.3.13: Mean total PRI of LBP reported by people, divided in groups by country, for each level of the EQ-5D dimensions
Abbreviations: EQ-5D, Quality of Life; PRI, Present Rating Index.

The relationship between QoL and LBP quality and intensity was hypothesised (hypotheses 10 & 11) as following:

Hypothesis 0 (null): In people with iSCI there is no significant correlation between QoL (EQ-5D index or EQ-VAS) and quality (sensory, affective or total PRI) of LBP for each national group.

Hypothesis 10a: In people with iSCI there is a significant correlation between QoL (EQ-5D index or EQ-VAS) and sensory dimension of LBP for each national group.

Hypothesis 10b: In people with iSCI there is a significant correlation between QoL (EQ-5D index or EQ-VAS) and affective dimension of LBP for each national group.

Hypothesis 10c: In people with iSCI there is a significant correlation between QoL (EQ-5D index or EQ-VAS) and total PRI of LBP for each national group.

Hypothesis 0 (null): In people with iSCI there is no significant correlation between QoL (EQ-5D index or EQ-VAS) and intensity of LBP (on the NRS or evaluative) for each national group.

Hypothesis 11a: In people with iSCI there is a significant correlation between QoL (EQ-5D index or EQ-VAS) and intensity of current LBP for each national group.

Hypothesis 11b: In people with iSCI there is a significant correlation between QoL (EQ-5D index or EQ-VAS) and intensity of LBP over the last one month for each national group.

Hypothesis 11c: In people with iSCI there is a significant correlation between QoL (EQ-5D index or EQ-VAS) and intensity of LBP over the last three months for each national group.

Hypothesis 11d: In people with iSCI there is a significant correlation between QoL (EQ-5D index or EQ-VAS) and overall evaluative intensity of LBP (PPI) for each national group.

It was confirmed that as the mean quality (sensory, affective and total PRI) of LBP became worse, people from the USA *classified* their health status as worse but it was only in the affective dimension that the correlation passed the Bonferroni α-level of significance (Table 9.3.6). Within the same group, when the affective dimension of LBP became worse, people *perceived* their self-rated health as highly significantly worse too (Table 9.3.6).

Analysis of the pooled data (Chapter 7, Section 7.9) showed that when intensity of LBP increases then QoL becomes worse. Here, it was found that the worse the intensity of LBP (intensity of current, of last one and three months and evaluative LBP), the worse the QoL for each individual national group. All correlations within each group confirmed that when the intensity of LBP increases then people classify and perceive their health status as worse. The strengths of the correlations were moderate to strong, despite on some occasions not being statistically significant (Table 9.3.7, Figure 9.3.16). Finally, no significant interaction effect between country and evaluative PPI of

LBP on either the EQ-5D index or EQ-VAS was found; for EQ-5D: p=0.29, (F=1.22, η^2=0.0228, two-way ANOVA, n=130); for EQ-VAS: p=0.19, (F=1.45, η^2=0.0055, two-way ANOVA, n=130).

Table 9.3.6: Correlations between quality of LBP and health status within each national group

		USA	UK	GR
EQ-5D Index	S-PRI	r=-0.26, n=76 p=0.02[1] 95%CI -0.44, -0.05	r=-0.40, n=35 p≤0.01[1] 95%CI -0.64, -0.09	ρ=-0.20, n=30 p=0.26, 95%CI -0.52, 0.17
	A-PRI	r=-0.38, n=76 **p≤0.001***** 95%CI -0.55, -0.19	r=-0.25, n=35 p=0.14, 95%CI -0.52, -0.08	ρ=0.05, n=30 p=0.77, 95%CI -0.31, 0.40
	Total PRI	r=-0.29 , n=75 p=0.009[1] 95%CI -0.46, -0.08	r=-0.20, n=33 p=0.25, 95%CI -0.51, 0.15	ρ=-0.21, n=30 p=0.25, 95%CI -0.52, 0.17
EQ-VAS	S-PRI	r=-0.23, n=76 p=0.03[1] 95%CI -0.42, -0.02	r=-0.27, n=35 p=0.10, 95%CI -0.54, 0.06	r=-0.18, n=30 p=0.33, 95%CI -0.50, 0.19
	A-PRI	r=-0.37, n=76 **p≤0.001***** 95%CI -0.53, -0.17	r=-0.21, n=35 p=0.22, 95%CI -0.50, 0.12	r=-0.17, n=30 p=0.36, 95%CI -0.50, 0.20
	Total PRI	r=-0.19, n=75 p=0.09, 95%CI -0.38, 0.02	r=-0.02, n=33 p=0.88, 95%CI -0.36, 0.32	ρ=-0.18, n=30 p=0.32, 95%CI -0.50, 0.19

[1]not significant post Bonferroni correction; **in bold:** significant following application of the Bonferroni correction;

Abbreviations: EQ-5D, Quality of Life; EQ-VAS, Quality of Life Visual Analogue Scale; PRI, Present Rating Index; S-PRI, Sensory PRI; A-PRI, Affective PRI;

Statistical tests: r, Pearson's correlation; ρ, Spearman's rank correlation rho.

Table 9.3.7: Correlations between intensity of LBP and health status within each national group

Correlations between		USA n=78	UK n=32	GR n=3
Current LBP	With EQ-5D index	r=-0.39, **p≤0.001*** ** 95%CI -0.55, -0.20	r=-0.70, **p≤0.001*** ** 95%CI -0.83, -0.47	n/a
	With EQ-VAS	r=-0.38, **p≤0.001*** ** 95%CI -0.55, -0.19	r=-0.49, p=0.003 [1] 95%CI -0.71, -0.18	n/a
LBP intensity last 1 month	With EQ-5D index	r=-0.35, **p≤0.001*** ** 95%CI -0.52, -0.15	r=-0.58, **p≤0.001*** ** 95%CI -0.76, -0.30	n/a
	With EQ-VAS	r=-0.47, **p≤0.001*** ** 95%CI -0.46, -0.08	r=-0.32, p=0.07 95%CI -0.71, 0.18	n/a
LBP intensity last 3 months	With EQ-5D index	r=-0.29, p≤0.01 [1] 95%CI -0.56, -0.21	r=-0.49, p=0.004 [1] 95%CI -0.57, 0.06	n/a
	With EQ-VAS	r=-0.40, **p≤0.001*** **	r=-0.29, p=0.09	n/a
Evaluative LBP intensity	With EQ-5D index	r=-0.37, n=71 **p≤0.001*** ** 95%CI -0.55, -0.15	r=-0.37, n=30 p=0.03 [1] 95%CI -0.64, -0.01	r=-0.39, n=29 **p≤0.001*** ** 95%CI -0.64, -0.02
	With EQ-VAS	r=-0.47, n=71 **p≤0.001*** ** 95%CI -0.63, -0.28	r=-0.37, n=30 p=0.04 [1] 95%CI -0.64, -0.01	r=-0.34, n=29 p=0.06 95%CI -0.62, 0.02

n/a: Data from the Greek group on the intensity of LBP was only given by three respondents thus will not be examined[39]. Data for the evaluative PPI intensity was used normally; [1]not significant post Bonferroni correction; **significant at p≤0.01; **in bold:** significant following application of the Bonferroni correction; Abbreviations: EQ-5D, Quality of Life; EQ-VAS, Quality of Life Visual Analogue Scale; LBP, Low Back Pain; PRI, Present Rating Index.
Statistical tests: r, Pearson's correlation.

[39] For an explanation of why there are only three respondents from Greece answering this question refer back to Chapter 6, Section 6.2.7.

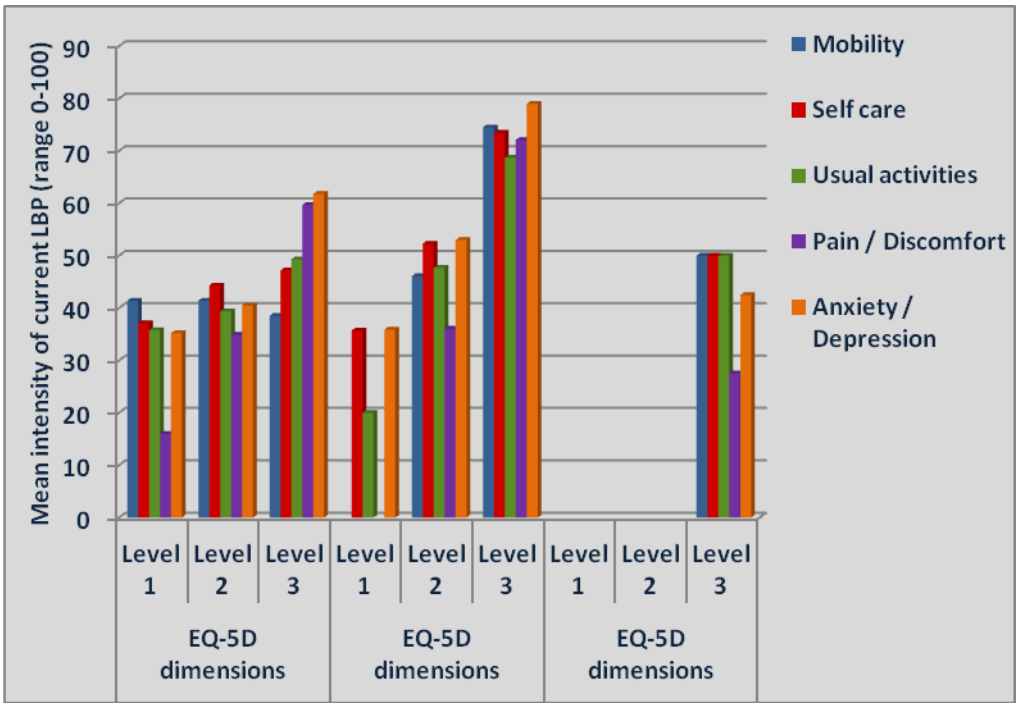

Figure 9.3.14: Mean intensity score of current LBP reported by people, divided in groups per country, for each level of the EQ-5D dimensions. In the Greek group only 1 respondent reported being on level 1 or 2 and thus no mean score can be given for these two levels.

Abbreviations: EQ-5D, Quality of Life; EQ-VAS, Quality of Life Visual Analogue Scale; PRI, Present Rating Index.

Part 4; SCIM III: Pain and function within and across nations

9.4.1 Introduction

This is the final section of this chapter which aims to explore the functional independence of the respondents within each of the three participating countries. This chapter will explore the relations between the experience of pain and function.

In Chapter 8 as part of the procedure followed to validate the translation of GR-SCIM III, data from the Greek group was analysed separately to the rest of the data. To avoid duplicating information the Greek group will not be re-analysed here unless new data is examined. Referencing back to the previous chapter will be made as appropriate.

9.4.2 Bonferroni correction

For all three groups from the participating countries the main variables of interest were used in 25 different tests in the cross-national analysis thus the α-level of statistical significance set by Bonferroni was p≤0.002 (Appendix 9: Table 9.d.1.1).

9.4.3 Function across nations; general results

Among the three participating countries people from Greece reported the best functional independence (mean±SD 76.1±21.3) followed by people from the USA (67.4±20.5) and then the UK (61.1±20.4) (Figure 9.4.1; Table 9.4.1; Appendix 9: Table 9.d.2.1). Greeks reported the best function score for all subscales apart from "self-care" in which people from the USA scored better than all others (Table 9.4.1). The groups from the three participating countries differed significantly in three of the five function subscales; for "respiration and sphincter management": p≤0.001, (F=10.7, One-way ANOVA, n=219); for "mobility indoors and outdoors": p≤0.001, (F=7.26, One-

way ANOVA, n=219); and for total SCIM: p=0.002, (F=6.35, One-way ANOVA, n=219). Post hoc analysis using Bonferroni showed that for the first two subscales people from Greece scored significantly better than people from both the USA and the UK and for the third subscale people from the USA scored better than from people the UK (Table 9.4.1).

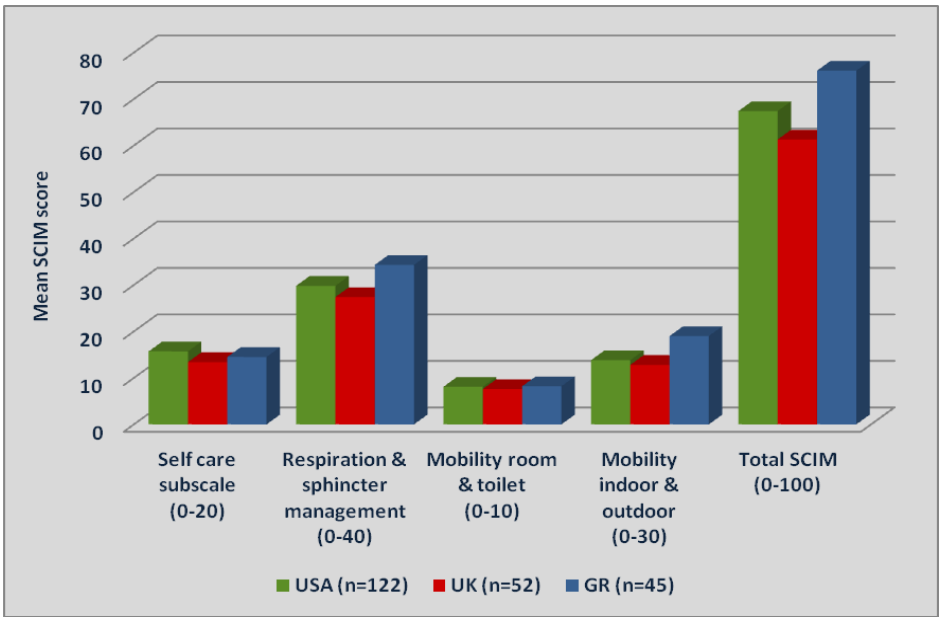

Figure 9.4.1: Mean function scores and statistical differences in function between national group
Abbreviation: SCIM, Spinal Cord Independence Measure.

Table 9.4.1: Characteristic of SCIM per country and differences between countries

	USA	UK	Greece	Between national groups Statistical Tests
Self-care (range 0-20)	15.7±5.2	13.4±5.7	14.5±5.1	p=0.03[1], F=3.36, n=219
Respiration & sphincter management (range 0-40)	29.8±7.4	27.4±7.7	34.3±7.5	**p≤0.001*****, F=10.7, n=219 USAvsGR: I-J=-6.9, **p≤0.001***** 95%CI-10.6, -3.2 UKvsGR: I-J=-6.9, **p≤0.001***** 95%CI-10.6, -3.2
Mobility room and toilet (range 0-10)	8.1±3.1	7.6±3.4	8.2±2.5	p=0.58, F=0.54, n=219
Mobility indoors & outdoors (range 0-30)	13.8±8.6	12.8±8.2	19.0±9.9	**p≤0.001*****, F=7.26, n=219 USAvsGR: I-J=-5.1, **p=0.03**, 95%CI-8.9, -1.4 UKvsGR: I-J=-6.27, **p=0.02*** 95%CI-810.6, -1.9
Total SCIM (range 0-100)	67.4±20.5	61.1±20.4	76.1±21.3	**p=0.002****, F=6.36, n=219 USAvsUK: I-J=-8.7, **p=0.04*** 95%CI-17.4, 14.5 UKvsGR: I-J=-14.9, **p≤0.01**** 95%CI-25.1, -4.8

[1]not significant post Bonferroni correction; *Significant at p≤0.05 level, **Significant at p≤0.01 level, ***Significant at p≤0.001 level, **in bold:** significant following application of the Bonferroni correction or Bonferroni post hoc;
Abbreviation: SCIM, Spinal Cord Independence Measure.
Statistical test: F, One-way ANOVA, I-J, Bonferroni Post hoc

9.4.4 Function across nations; relation to demographic profile characteristics

9.4.4.1 Gender across nations

Earlier analysis (Chapter 8, Sections 8.1.5 and 8.2.4) found no gender differences for any of the subscales or the total SCIM for the Greek group or the combined data from the rest of the respondents. Using two-way ANOVA the country of residence in combination with gender could not predict function (Appendix 9: Table 9.d.3.6). Examining the data between groups from each country separately, females, overall, reported better function than males within the US and Greek groups and males better than females in the UK group. The group with the lowest total SCIM score was females from UK (57±19.8) (Appendix 8: Table 8.3.1; Appendix 9: Table 9.d.3.1). Within each

group from the three countries separately, females and males reported very similar function on the SCIM subscales (Appendix 9: Table 9.d.3.2). When function was examined based on the presence of MSKP within each gender no significant differences were found (Appendix 9. Table: 9.d.3.8, 9.d.3.9).

9.4.4.2 Cause of injury across nations

Earlier, no significant differences were found between people with traumatic and non-traumatic injury from Greece or the rest of the group on SCIM or its subscales (Chapter 8, Sections 8.1.5 and 8.2.4). No significant interaction effect between cause of injury and country of residence on function was found (Appendix 9: Table 9.d.3.6). Within each national group separately, generally those with a non-traumatic injury had a better function. No group or subscale for people with traumatic and non-traumatic injury differed significantly in their mean function reports (Appendix 9: Table 9.d.3.2). Between countries, people from Greece with a non-traumatic injury reported better SCIM and its subscales (Appendix 9: Table 9.d.3.4).

9.4.4.3 Level of injury

Within each group, separately, those with paraplegia reported better function than those with tetraplegia (Appendix 9: Table 9.d.3.5) which matched earlier findings from the pooled data (Chapter 8, Sections 8.1.5 and 8.2.4). However, these differences reached significant levels only within the USA group (Table 9.4.2) in the case of "mobility in room and toilet". For this subscale a significant difference was found for the pooled group. Between the groups from the three countries, people with paraplegia from Greece reported the best function of all respondents (total SCIM 83.3±13.6) and people with tetraplegia from the UK the worst (total SCIM 55.6±25.6) (Appendix 9: Table 9.d.3.5). Finally, no significant interaction effect between the type of injury and country of residence on any of the subscales and the total SCIM was found (Appendix 9: Table 9.d.3.6).

Table 9.4.2: Differences on function between people with tetraplegia and paraplegia within each national group

	Self-care	Respiration & sphincter management	Mobility room and toilet	Mobility indoors & outdoors	Total SCIM
USA n=122	U=170.5 p=0.07	t=0.15, df119 p=0.87 95% CI -2.3, 2.6	t=-3.71, df120 **p≤0.001*** ** 95% CI -3.0, 0.9	t=-0.59, df120 p=0.55 95% CI -4.0, 2.1	t=-2.14, df120 p=0.03[1] 95% CI -15.1, -0.6
UK n=50	U=195 p=0.02[1]	t=-1.08, df46 p=0.18 95% CI -6.4, 1.9	t=-2.65, df48 p≤0.01[1] 95% CI -4.2, 0.5 U=1370.5 p=0.005[1]	t=-0.98, df48 p=0.32 95% CI -6.9, 2.3	t=-1.77, df48 p=0.08 95% CI -21.6, 1.3
Greece	Refer back to Chapter 8, Table 8.2.6				

[1]not significant post Bonferroni correction; ***Significant at p≤0.001 level; **in bold:** significant following application of the Bonferroni correction;
Abbreviation: SCIM, Spinal Cord Independence Measure.
Statistical tests: t, Independent t-test.

9.4.4.4 Age and time since injury across nations

Earlier it was found that either age or time since injury did not correlate significantly with function or its subscales (Chapter 8, Sections 8.1.5 and 8.2.4). Examining each group separately from all three countries also showed no significant correlation between age and total function or its subscales though, again, the direction of the correlations tended to show a decrease in function with an increase in age but the relation, was of small strength (Appendix 9: Table 9.d.3.7). Increase in the time since injury correlated with an overall decrease in function which in no case was statistically significant and usually it was of small strength (Appendix 9: Table 9.d.3.7). However, the interaction effect between age and country of residence was significant on the total function score (p=0.001, Wald χ^2=16.42, df3, n=211). In particular, the effect was that with increasing age, people from Greece were more likely to report better function (p=0.04. b=0.20, SE=0.09, Wald χ^2=4.1, df1, n=50). Finally, the interaction effect between time since injury and country of residence on the total function score was not significant past the Bonferroni α-level (p=0.009, Wald χ^2=11.60, df3, n=218).

9.4.5 Function across nations; relation to pain, LBP and MSKP

Examining the interaction effect of pain, LBP or MSKP presence and living in one of the three participating countries on function was not significant (Table 9.4.3). Part of the first hypothesis theme was to investigate differences in function based on the presence or not of the pain categories under examination (hypothesis 3).

The hypothesis was examined per group from each of the three countries:

Hypothesis 0 (null): In people with iSCI there is no significant difference in the function (total SCIM or subscales) between those with pain, MSKP or LBP and those without, for each national group.

Hypothesis 3a: In people with iSCI there is no significant difference in the function (total SCIM or subscales) between those with pain and those without, for each national group.

Hypothesis 3b: In people with iSCI there is no significant difference in the function (total SCIM or subscales) between those with MSKP and those without, for each national group.

Hypothesis 3c: In people with iSCI there is no significant difference in the function (total SCIM or subscales) between those with LBP and those without, for each national group.

Looking at the data for pain in general, interestingly, people with pain particularly from the USA and the UK scored better on total function and its subscales than people without pain (Appendix 9: Table 9.d.4.1, Appendix 8: Table 8.4.1) though the differences were not statistically significant (Table 9.4.4; Chapter 8: Table 8.2.7). Between the three groups, people with the best total function were those with no pain from Greece (Appendix 9: Table 9.d.4.1, Appendix 8: Table 8.4.1). Within each group, people without MSKP seemed to have better function overall than those with MSKP for the UK and Greek groups. However, in no case did those with and without MSKP differ significantly on their SCIM or subscale mean scores (Table 9.4.4; Chapter 8: Table 8.2.7; Appendix 9: Tables 9.d.4.1; Appendix 8: Table 8.4.1). Finally, in the case of LBP, it

was noticed that in all three groups, people with LBP reported better function than those without LBP. However, this difference was again not significant within any country (Table 9.4.4; Chapter 8: Table 8.2.7; Appendix 9: Tables 9.d.4.1, Appendix 8: Table 8.4.1).

Table 9.4.3: Interaction effect between country of residence and pain presence on function

	Interaction effect of pain *country on DV	Interaction effect of MSKP *country on DV	Interaction effect of LBP *country on DV
Self-care	F=3.27, p=0.04 [1] η^2=0.0034 n=219	F=0.44, p=0.63 η^2=0.0005 n=213	F=0.05, p=0.95 η^2=0.00005 n=210
Respiration & sphincter management	F=4.37, p≤0.01 [1] η^2=0.0022 n=219	F=1.02, p=0.36 η^2=0.00056 n=213	F=0.41, p=0.66 η^2=0.00020 n=210
Mobility room and toilet	F=6.24, p=0.02 [1] η^2=0.0070 n=219	F=0.37, p=0.69 η^2=0.0004 n=213	F=0.95, p=0.38 η^2=0.0011 n=210
Mobility indoors & outdoors	F=1.66, p=0.19 η^2=0.0039 n=219	F=0.57, p=0.56 η^2=0.0013 n=213	F=0.07, p=0.92 η^2=0.00017 n=210
Total SCIM	F=4.65, p≤0.01 [1] η^2=0.0034 n=219	F=0.76, p=0.46 η^2=0.0005 n=212	F=0.01, p=0.99 η^2=0.000007 n=210

[1]not significant post Bonferroni correction;
Abbreviation: SCIM, Spinal Cord Independence Measure.
Statistical test: F, Two-way ANOVA.

Table 9.4.4: Differences in function between groups with and without pain, LBP, or MSKP per country

	Self-care subscale	Respiration & sphincter management	Mobility room & toilet	Mobility indoors & outdoors	Total SCIM
USA					
Pain n=122	U=370.5 p=0.71 ES: r=0.03	U=323.5 p=0.38 ES: r=0.07	U=364.5 p=0.63 ES: r=0.04	U=379 p=0.79 ES: r=0.02	U=348 p=0.54 ES: r=0.05
Current LBP n=166	U=1397.5 p=0.53 ES: r=0.07	t=-1.03, df114 p=0.30 95%CI -4.0, 1.2 ES: d=0.20	U=1460.5 p=0.78 ES: r=0.02	t=-0.98, df114 p=0.32 95%CI -5.0, 1.6 ES: d=0.18	t=-1.38, df113 p=0.16 95%CI -12.7, 2.2, ES: d=0.25
MSKP n=120	t=-1.18, df118 p=0.24 95%CI -3.3, 0.8 ES: d=0.22	t=-0.8, df117 p=0.41 95%CI -3.7, 1.5 ES: d=0.14	t=-1.52, df118 p=0.13 95%CI -2.0, 0.2 ES: d=0.30	t=-1.16, df118 p=0.24 95%CI -5.1, 1.3 ES: d=0.22	t=-1.24, df117 p=0.21 95%CI -12.1, 2.7, ES: d=0.24
UK					
Pain n=52	U=5.5 p=0.03[1] ES: r=0.29	U=6.5 p=0.03[1] ES: r=0.28	U=4.0 p=0.02[1] ES: r=0.32	U=4.0 p=0.02[1] ES: r=0.30	U=1.5 p=0.02[1] ES: r=0.31
Current LBP n=52	U=270 p=0.10 ES: r=0.01	t=0.40, df49 p=0.68 95%CI -3.8, 5.8 ES: d=0.12	U=212.5 p=0.20, ES: r=0.17	t=-0.74, df49 p=0.46 95%CI -7.0, 3.2 ES: d=0.21	t=-0.66, df49 p=0.51 95%CI -16.9, 8.5, ES: d=0.17
MSKP n=51	t=-0.04, df49 p=0.96 95%CI -3.3, 3.2 ES: d=0.01	t=0.50, df49 p=0.61 95%CI -3.3, 5.5 ES: d=0.15	U=302.5 p=0.74 ES: r=0.04	t=-0.22, df49 p=0.82 95%CI -5.2, 4.2 ES: d=0.05	U=314 p=0.92 ES: r=0.01
Greece	Refer back to Chapter 8, Section 8.2.8				

[1]not significant post Bonferroni correction;
Abbreviation: SCIM, Spinal Cord Independence Measure; LBP, Low Back Pain; MSKP, Musculoskeletal Pain.
Statistical tests: U, Mann-Whitney U test; t, Independent t-test.

9.4.6 Function across nations; relation to pain/LBP days, free weeks, onset

Previous analysis did not find any statistically significant changes in function when there was an increase in the number of pain or LBP days felt in a month for the Greek or the pooled group (Chapter 8, Sections 8.1.7 and 8.2.6). Analysis for each national group separately confirmed that an increase in the number of LBP days felt in the month did not correlate significantly with a change in function score (Table 9.4.5). People who had more pain days were more likely to report worse function scores but

the correlations were not statistically significant although, occasionally, correlations were of moderate strength and for the Greek group they were of high strength (Table 9.4.5; Appendix 8: Table 8.5.2). In addition, no significant interaction effects were found between the country of residency and the number of LBP days or the frequency of LBP breaks on the total function score or any of its subscales (Table 9.4.6).

Overall, for each individual country, the frequency of LBP-free weeks did not correlate significantly with changes in function. The only significant correlation was within the UK group in the case of "self-care" ($p=0.002$, $\rho=-0.55$, Spearman's ρ, $n=27$) (Table 9.4.5). Correlations for the UK and the Greek group, despite not being statistically significant, were often strong and this should be taken into account for the practical significance.

Examining function in relation to pain or LBP onset post iSCI the country of residence in combination with pain or LBP onset did not affect the total function or any of its subscales (Tables 9.4.6 and 9.4.7). Finally, the relationship between pain or LBP onset, post iSCI, and function was part of the second hypotheses theme (hypothesis 7) and is here tested per each group from the individual countries.

Hypothesis 0 (null): In people with iSCI there is no significant correlation between function (total SCIM and subscales) and the onset of pain or LBP, post iSCI, for each national group.

Hypothesis 7a: In people with iSCI there is a significant correlation between function (total SCIM and subscales) and the onset of pain, post iSCI, for each national group.

Hypothesis 7a: In people with iSCI there is a significant correlation between function (total SCIM and subscales) and the onset of LBP, post iSCI, for each national group.

Three things were noticed during the analysis of these correlations. First, only one correlation was statistically significant and this was within the Greek group between LBP onset and "mobility in room and toilet" ($p\leq0.001$, $\phi=0.75$, Phi correlation, $n=29$). Second, within the USA and the UK groups the strength of the correlations were weak, particularly within the UK group, whereas within the Greek group the strength of the

correlations was very high. Finally, within the USA and UK groups the direction of the correlations was negative, which meant that the earlier the pain or LBP onset the better the function of the respondent, possibly showing a functional adjustment to the presence of pain or LBP. However, the opposite was found within the Greek group where the direction of the correlations was positive, thus the earlier the pain or LBP onset, post iSCI, the worse the function (Table 9.4.5).

Table 9.4.5: Correlations between function and pain/LBP onset port iSCI or pain/LBP days felt per month or frequency of pain/LBP free weeks within each national group

	Self care subscale	Respiration & sphincter management	Mobility room & toilet	Mobility indoors & outdoors	Total SCIM
USA					
Pain onset n=108	ρ=-0.17, p=0.06, 95%CI -0.33, 0	ρ=-0.11, p=0.25, 95%CI -0.28, 0.06	ρ=-0.24, p≤0.01[1] 95%CI -0.39, 0.07	ρ=-0.29, p=0.02[1], 95%CI -0.61, -0.12	ρ=-0.25, p=0.008[1] 95%CI -0.40, -0.08
LBP onset n=77	ρ=-0.09, p=0.41, 95%CI -0.03, 0.12	ρ=0.17 , p=0.13, 95%CI -0.04, 0.37	ρ=-0.11, p=0.30, 95%CI -0.31, 0.10	ρ=-0.19, p=0.09, 95%CI -0.38, 0.02	ρ=-0.07, p=0.53 , 95%CI -0.28, 0.16
Pain days	ρ=-0.06, p=0.47, n=113	ρ=-0.19, p=0.04[1] n=113	ρ=-0.09, p=0.33, n=113	ρ=0.04, p=0.64, n=113	ρ=-0.02, p=0.78, n=113
LBP days felt per month	ρ=-0.15, p=0.17, n=84	ρ=0.09, p=0.39, n=84	ρ=-0.07, p=0.48, n=84	ρ=0.05, p=0.65, n=84	ρ=-0.04, p=0.64, n=84
Pain-free weeks	ρ=-0.07, p=0.47, n=104	ρ=-0.18, p=0.06, n=104	ρ=-0.04, p=0.63, n=104	ρ=0.02, p=0.81, n=104	ρ=-0.08, p=0.39, n=104
LBP-free weeks	ρ=-0.09, p=0.47, n=64	ρ=-0.10, p=0.42, n=64	ρ=-0.12, p=0.32, n=64	ρ=0.05, p=0.65, n=64	ρ=-0.03, p=0.76, n=64
UK					
Pain onset n=46	ρ=0.09, p=0.55, 95%CI -0.20, 0.37	ρ=-0.06, p=0.67, 95%CI -0.34, 0.23	ρ=-0.01, p=0.94, 95%CI -0.30, 0.28	ρ=-0.10, p=0.50, 95%CI -0.37, 0.19	ρ=-0.001, p=0.99, 95%CI -0.29, 0.29
LBP onset n=34	ρ=-0.06, p=0.71, 95%CI -0.37, 0.27	ρ=-0.30, p=0.07, 95%CI -0.56, 0.03	ρ=-0.04, p=0.78, 95%CI -0.36, 0.29	ρ=-0.14, p=0.41, 95%CI -0.44, 0.19	ρ=-0.14, p=0.43, 95%CI -0.44, 0.19
Pain days	ρ=-0.13, p=0.35, n=50	ρ=-0.12, p=0.37, n=50	ρ=-0.02, p=0.88, n=50	ρ=-0.21, p=0.13, n=50	ρ=-0.02, p=0.87, n=50
LBP days felt per month	ρ=-0.32, p=0.06, n=35	ρ=-0.003, p=0.98, n=35	ρ=-0.31, p=0.06, n=35	ρ=-0.03, p=0.86, n=35	ρ=-0.15, p=0.37, n=35
Pain-free weeks	ρ=-0.22, p=0.13, n=48	ρ=-0.09, p=0.51, n=48	ρ=-0.19, p=0.18, n=48	ρ=0.08, p=0.58, n=48	ρ=-0.10, p=0.47, n=48
LBP-free weeks	ρ=-0.55, **p=0.002**** n=27	ρ=-0.20, p=0.29, n=29	ρ=-0.52, p=0.004[1], n=29	ρ=-0.21, p=0.25, n=29	ρ=-0.42, p=0.02[1], n=77
Greece	Refer back to Chapter 8, Table 8.1.8; Appendix 8: Tables 8.5.2, 8.5.4				

[1]not significant post Bonferroni correction; **Significant at p≤0.01 level; **in bold:** significant following application of the Bonferroni correction;
Abbreviation: SCIM, Spinal Cord Independence Measure; LBP, Low Back Pain.
Statistical tests: ρ, Spearman's rank correlation rho

Table 9.4.6: Interaction effects between country of residence and LBP days or LBP-free weeks or LBP onset post iSCI on function

	Interaction effect of LBP days *country on DV	Interaction effect of LBP free weeks *country on DV	Interaction effect of LBP onset post iSCI *country on DV
Self-care	F=0.54, p=0.77 η^2=0.0020 n=151	F=0.91, p=0.51 η^2=0.00593 n=123	F=0.38, p=0.92 η^2=0.00223 n=142
Respiration & sphincter management	F=0.37, p=0.89 η^2=0.0008 n=151	F=0.33, p=0.96 η^2=0.00136 n=123	F=0.90, p=0.51 η^2=0.00259 n=142
Mobility room and toilet	F=0.48, p=0.82 η^2=0.00169 n=151	F=0.30, p=0.97 η^2=0.00192 n=123	F=0.54, p=0.81 η^2=0.0029 n=142
Mobility indoors & outdoors	F=1.87, p=0.09 η^2=0.01628 n=151	F=2.08, p=0.03 [1] η^2=0.0301 n=123	F=1.66, p=0.19 η^2=0.0039 n=142
Total SCIM	F=0.88, p=0.50 η^2=0.00243 n=151	F=0.81, p=0.60 η^2=0.00385 n=123	F=0.48, p=0.86 η^2=0.0019 n=142

[1]not significant post Bonferroni correction;
Abbreviation: SCIM, Spinal Cord Independence Measure.
Statistical test: F, Two-way ANOVA.

9.4.7 Function across nations; relation to pain extent

Previous analysis (Chapter 8, Sections 8.1.8 and 8.2.7) found no significant relationship between the number of painful areas on the body and function. This was confirmed when examining data within the groups from each country (Appendix 9: Table 9.d.5.1). In addition, using two-way ANOVA the interaction effect between the number of areas with pain and the country of residence on total function or its subscales was not found to be significant (Appendix 9: Table 9.d.5.1).

Table 9.4.7: Interaction effects between country of residence and pain days or pain-free weeks or pain onset post iSCI on function

	Interaction effect of pain days *country on DV - Two-way ANOVA	Interaction effect of pain free weeks *country on DV - Two-way ANOVA	Interaction effect of pain onset post iSCI *country on DV - Two-way ANOVA
Self-care	F=1.98, p=0.18 η^2=0.0004 n=163	F=0.15, p=0.97 η^2=0.0006 n=152	F=1.31, p=0.26 η^2=0.0036 n=154
Respiration & sphincter management	F=0.82, p=0.48 η^2=0.0008 n=163	F=0.25, p=0.93 η^2=0.0005 n=152	F=0.47, p=0.75 η^2=0.0007 n=154
Mobility room and toilet	F=1.93, p=0.12 η^2=0.0044 n=163	F=0.27, p=0.92 η^2=0.0012 n=152	F=0.74, p=0.56 η^2=0.0024 n=154
Mobility indoors & outdoors	F=0.36, p=0.77 η^2=0.0018 n=163	F=0.68, p=0.63 η^2=0.0064 n=152	F=2.04, p=0.09 η^2=0.0013 n=154
Total SCIM	F=1.28, p=0.28 η^2=0.0019 n=163	F=0.11, p=0.98 η^2=0.0003 n=152	F=1.65, p=0.16 η^2=0.0003 n=154

Abbreviation: SCIM, Spinal Cord Independence Measure.
Statistical test: F, Two-way ANOVA.

9.4.8 Function across nations; relation to quality and intensity of LBP

Part of the third hypothesis theme was an examination of the relationships between quality and intensity of LBP and function (hypotheses 12 & 13). Previous analysis found no significant correlations between quality or intensity of LBP and function when the pooled group was examined though the correlation with increased intensity was stronger and always negative (Chapter 8: Tables 8.2.10, 8.2.11, 8.2.8.1 and 8.2.8.2). The combination of total function and where respondents resided did not have a significant effect on either the quality or the intensity of LBP (Table 9.4.8).

Table 9.4.8: Interaction effects of country of residence and total function on quality or intensity of LBP

	Interaction effect of total SCIM *country on DV
S-PRI	p=0.01[1], n=152, Wald χ^2=10.62, df3, Likelihood ration χ^2=10.26, df3, p=0.016[1]
A-PRI	p=0.01[1], n=152, Wald χ^2=10.62, df3, Likelihood ration χ^2=10.26, df3, p=0.016[1]
Total PRI	p=0.01[1], n=152, Wald χ^2=10.62, df3, Likelihood ration χ^2=10.26, df3, p=0.016[1]
Intensity current LBP	p=0.01[1], n=152, Wald χ^2=10.62, df3, Likelihood ration χ^2=10.26, df3, p=0.016[1]
Intensity LBP over 1 month	p=0.01[1], n=152, Wald χ^2=10.62, df3, Likelihood ration χ^2=10.26, df3, p=0.016[1]
Intensity LBP over 3 months	p=0.01[1], n=152, Wald χ^2=10.62, df3, Likelihood ration χ^2=10.26, df3, p=0.016[1]
Evaluative PPI intensity of LBP	p=0.01[1], n=152, Wald χ^2=10.62, df3, Likelihood ration χ^2=10.26, df3, p=0.016[1]

[¥]The Greek group was excluded due to insufficient data;
[1] not significant post Bonferroni correction,
Abbreviations: MSKP, Musculoskeletal Pain; LBP, Low Back Pain; SE, Standard Error;
Statistical tests: χ^2, Likelihood ratio Chi-square; Wald test chi-square distribution;

The hypotheses across nations were:

Hypothesis 0 (null): In people with iSCI there is no significant correlation between function (total SCIM and subscales) and quality (sensory, affective or total PRI) of LBP, for each national group.

Hypothesis 12a: In people with iSCI there is a significant correlation between function (total SCIM and subscales) and sensory dimension of LBP, for each national group.

Hypothesis 12b: In people with iSCI there is a significant correlation between function (total SCIM and subscales) and affective dimension of LBP, for each national group.

Hypothesis 12a: In people with iSCI there is a significant correlation between function (total SCIM and subscales) and total PRI of LBP, for each national group.

Hypothesis 0 (null): In people with iSCI there is no significant correlation between function (total SCIM and subscales) and intensity of LBP, for each national group.

Hypothesis 13a: In people with iSCI there is a significant correlation between function (total SCIM and subscales) and intensity of current LBP, for each national group.

Hypothesis 13b: In people with iSCI there is a significant correlation between function (total SCIM and subscales) and intensity LBP over the last one month, for each national group.

Hypothesis 13c: In people with iSCI there is a significant correlation between function (total SCIM and subscales) and intensity LBP over the last three months, for each national group.

Hypothesis 13d: In people with iSCI there is a significant correlation between function (total SCIM and subscales) and evaluative PPI of LBP, for each national group.

All correlations maintained a negative direction, thus the worse the quality or intensity of LBP, the worse the function. This was true across all three national groups (Table 9.4.9, Chapter 8: Tables 8.2.10 and 8.2.11). Overall correlations between function and quality of LBP remained not significant and weak. The correlation between LBP intensity and function was stronger within each group, as found for the total group, and within the UK and the Greek groups statistically significant too, on some occasions involving the subscales of "self-care", "mobility" and total function (Table 9.4.9).

In each country, people who reported higher LBP intensity (current or over the last one or three months) also reported significantly lower total function and most of the SCIM subscales (Table 9.4.10). This was not though, the result found in the case of the evaluative overall PPI of LBP as for the USA group no correlation between function and PPI was found, and for the UK group it was found only for the "mobility in room & toilet" subscale (Table 9.4.10) but for the Greek group it was significant for "self-care", "mobility indoors & outdoors" and total SCIM.

Table 9.4.9: Correlations between function and quality of LBP within each national group

		Self-care subscale	Respiration & sphincter management	Mobility room & toilet	Mobility indoors & outdoors	Total SCIM
S-PRI	USA n=60	r=0.07 p=0.56 95%CI -0.18, 0.31	r=-0.08 p=0.49 95%CI -0.32, 0.17	r=0.02 p=0.83 95%CI -0.23, 0.27	r=-0.01 p=0.92 95%CI -0.20, 0.24	r=-0.01 p=0.89 95%CI -0.20, 0.24
	UK n=29	r=-0.39 p=0.03[1] 95%CI -0.65, -0.04	r=-0.15 p=0.43 95%CI -0.48, 0.21	r=-0.27 p=0.15 95%CI -0.57, 0.10	r=-0.31 p=0.09 95%CI -0.60, 0.05	r=-0.37 p=0.03[1] 95%CI -0.64, -0.01
	Greece	Refer to Chapter 8, Table 8.2.10				
A-PRI	USA n=60	r=-0.08 p=0.50 95%CI -0.32, 0.17	r=-0.12 p=0.32 95%CI -0.36, 0.13	r=-0.12 p=0.34 95%CI -0.36, 0.13	r=0.02 p=0.84 95%CI -0.23, 0.27	r=-0.07 p=0.54 95%CI -0.18, 0.31
	UK n=29	r=-0.36 p=0.052 95%CI -0.63, 0.00	r=-0.10 p=0.58 95%CI -0.44, 0.27	r=-0.24 p=0.20 95%CI -0.55, 0.13	r=-0.27 p=0.18 95%CI -0.57, 0.10	r=-0.31 p=0.10 95%CI -0.60, 0.05
	Greece	Refer to Chapter 8, Table 8.2.10				
Total PRI	USA n=59	r=0.02 p=0.84 95%CI -0.23, 0.27	r=-0.16 p=0.20 95%CI -0.39, 0.09	r=-0.04 p=0.73 95%CI -0.29, 0.21	r=-0.02 p=0.87 95%CI -0.23, 0.27	r=-0.07 p=0.56 95%CI -0.31, 0.18
	UK n=28	r=-0.35 p=0.06 95%CI -0.64, 0.03	r=0.005 p=0.98 95%CI -0.36, 0.36	r=-0.26 p=0.16 95%CI -0.57, 0.13	r=-0.28 p=0.14 95%CI -0.59, 0.11	r=-0.28 p=0.14 95%CI -0.59, 0.11
	Greece	Refer to Chapter 8, Table 8.2.10				

[1]not significant post Bonferroni correction;
Abbreviation: SCIM, Spinal Cord Independence Measure; PRI, Present Rating Scale.
Statistical tests: r, Pearson's correlation.

Table 9.4.10: Correlations between function and intensity of LBP within each national group

		Self-care subscale	Respiration & sphincter management	Mobility room & toilet	Mobility indoors & outdoors	Total SCIM
Current LBP Intensity	USA n=61	r=-0.23 p=0.74	r=-0.29 p=0.02[1]	r=-0.28 p=0.02[1]	r=-0.16 p=0.19	r=-0.28 p=0.02[1]
	UK n=27	r=-0.54 p=0.03[1] ρ=0.5 p=0.008[1]	r=-0.22 p=0.25 ρ=-0.22 p=0.26	r=-0.43 **p=0.002**** ρ=-0.58 **p≤0.001*****	r=-0.45 p≤0.01[1] ρ=-0.46 p=0.01[1]	r=-0.53 p=0.004[1] ρ=-0.59 **p≤0.001 *** **
	Greece	Refer to Chapter 8, Table 8.2.11				
LBP intensity last 1 month	USA n=61	r=-0.17 p=0.17	r=-0.24 p=0.057	r=-0.19 p=0.13	r=-0.01 p=0.91	r=-0.17 p=0.17
	UK n=25	r=-0.55 **p=0.004*****	r=-0.08 p=0.68	r=-0.46 p≤0.01[1]	r=-0.40 p=0.04[1]	r=-0.47 p≤0.01[1]
	Greece	Refer to Chapter 8, Table 8.2.11				
LBP intensity last 3 month	USA n=60	r=-0.07 p=0.58	r=-0.22 p=0.08	r=-0.06 p=0.63	r=0.10 p=0.43	r=-0.07 p=0.58
	UK n=25	r=-0.43 **p=0.002****	r=-0.006 p=0.97	r=-0.46 p=0.02[1]	r=-0.39 p=0.051	r=-0.40 p=0.04[1]
	Greece	Refer to Chapter 8, Table 8.2.11				
Evaluative PPI of LBP	USA n=54	r=-0.09 p=0.49	r=-0.22 p=0.10	r=-0.08 p=0.55	r=0.13 p=0.34	r=-0.06 p=0.63
	UK n=25	r=-0.36 p=0.07	r=-0.12 p=0.54	r=-0.49 p≤0.01[1]	r=-0.28 p=0.16	r=-0.35 p=0.07
	Greece	Refer to Chapter 8, Table 8.2.11				

[1]not significant post Bonferroni correction; **in bold:** significant following application of the Bonferroni correction;
Abbreviation: SCIM, Spinal Cord Independence Measure; LBP, Low Back Pain; PPI, Present Pain Intensity.
Statistical test: r, Pearson's correlation.

9.4.9 Function across nations; relation to QoL

Previous analysis found that the correlation between function and QoL was positive, strong and highly statistically significant for the EQ-5D index; people who reported worse function also reported worse health status classification (Chapter 8: Table 8.2.12). Here, examining the US and UK groups and previously the Greek group (Chapter 8, Table 8.2.12) separately, it was found that in all cases the correlations were positive, moderate or

strong and highly statistically significant for classification of health status (Table 9.4.11). In the case of perception of health status, as function got worse, people also perceived their scored health status as worse but not significantly and the correlations were of small strength (Table 9.4.11). Consequently, the original results between function and QoL are maintained within each individual group from the three participating countries. Finally, when examining interaction effects some significant differences were found (Table 9.4.12). It was found that as function improves, people from the USA, the UK and Greece were more likely to *classify* themselves as better on health status (Table 9.4.12). Also, it was found that as function improves people from the USA were more likely to *perceive* their health status as better(Table 9.4.12).

Table 9.4.11: Correlations between health status and function within each national group

		Self-care subscale	**Respiration & sphincter management**	**Mobility room & toilet**	**Mobility indoors & outdoors**	**Total SCIM**
USA n=113	EQ-5D Index	r=0.46 **p≤0.001*** **	r=0.36 **p≤0.001*** **	r=0.48 **p≤0.001*** **	r=0.31, **p≤0.001*** **	r=0.45 **p≤0.001*** **
	EQ VAS	r=0.06 p=0.50	r=0.15 p=0.11	r=0.06 p=0.51	r=-0.05 p=0.57	r=0.05 p=0.52
UK n=43	EQ-5D Index	r=0.46 **p=0.002**** ρ=0.47 **p≤0.001*** **	r=0.39 p≤0.01[1]	r=0.37 p≤0.01[1] ρ=0.39 p=0.009[1]	r=0.32 p=0.03[1]	r=0.48 **p≤0.001*** **
	EQ VAS	r=0.13 p=0.39 ρ=0.20 p=0.18	r=0.07 p=0.63	r=-0.007 p=0.96 ρ=0.12 p=0.42	r=-0.09 p=0.56	r=0.03 p=0.84
Greece	Refer back to Chapter 8, Table 8.2.12					

[1]not significant post Bonferroni correction; **Significant at p≤0.01 level, ***Significant at p≤0.001 level; **in bold:** significant following application of the Bonferroni correction;
Abbreviation: SCIM, Spinal Cord Independence Measure; EQ-5D, Quality of Life, EQ-VAS, Quality of Life Visual Analogue Scale;
Statistical tests: r, Pearson's correlation.

Table 9.4.12: Interaction effect between country of residence and function (total SCIM) on health status

	Interaction effect of total SCIM *country on DV
EQ-5D	**p≤0.001*****, n=198, Wald χ^2=75.53, df3, Likelihood ration χ^2=63.98, df3, **p≤0.001***** USA*SCIM: b=0.009, SE=0.001, Wald χ^2=69.3, df1, 95% CI for Wald 0.007, 0.01, **p≤0.001***** UK*SCIM: b=0.009, SE=0.001, Wald χ^2=51.23, df1, 95% CI for Wald 0.007, 0.01, **p≤0.001***** GR*SCIM: b=0.009, SE=0.001, Wald χ^2=64.82, df1, 95% CI for Wald 0.007, 0.01, **p≤0.001*****
EQ-VAS	**p≤0.001*****, n=198, Wald χ^2=17.27, df3, Likelihood ration χ^2=16.56, df3, p≤0.01 [1] USA*SCIM: b=0.17, SE=0.07, Wald χ^2=4.91, df1, 95% CI for Wald 0.02, 0.32, p≤0.02 [1]

[1]not significant post Bonferroni correction; ***Significant at p≤0.001 level,
in bold: significant following application of the Bonferroni correction;
Abbreviations: MSKP, Musculoskeletal Pain; LBP, Low Back Pain; SE, Standard Error;
Statistical tests: χ^2, Likelihood ratio Chi-square; Wald test chi-square distribution;

9.5. Conclusion

The aim of this chapter has been to examine the same objectives to those examined in the three previous chapters which presented results, but looking at differences and correlations between and within the groups from the three participating countries. In addition, the interaction effect of the country of residence with another independent variable of interest (e.g. LBP presence, LBP quality etc.) on the main outcome looked at, was examined.

The main findings of this chapter were that Greeks differed in their type of injury and their mean age from respondents from the other countries. They reported the lowest percentage of pain but equal LBP. The quality of LBP was worse for people from the UK who also reported the worst function and classified their QoL lower. Greeks perceived their self-reported health as worse. The country of residence in combination with the demographic or injury-related characteristics could not predict the presence of the

categories of pain. It was found that as age increases people from the USA, UK and Greece are more likely to perceive their health status as worse. And, as time since injury increases, people from the USA are more likely to perceive their health status as better but Greeks, on the other hand, are more likely to perceive it as worse. Finally, it was found that as function improves people from the USA, the UK and Greece are more likely to report a better health state and people from the USA are more likely to also perceive a better self-rated health.

Chapter 10; Discussion

Chapter Brief Table of Contents

"The aim of argument, or of discussion,

should not be victory, but progress"

Joseph Joubert (1754 – 1824) - French Essayist and moralist

10.1 Introduction

This work was motivated by the need to explore pain at a specific body location in a group of people who are known to suffer very frequently from pain. People with SCI who are in pain can differ from other people in pain because certain features or consequences of the injury itself, alone or in interaction with the dimensions of pain, may precipitate or perpetuate their pain experience causing limitations to their daily lives by affecting function and QoL.

Using methods and tools, some for the first time, the original aim to describe the experience of pain and also to investigate its relationship with QoL and function in people with iSCI were fulfilled. Some results supported the literature, others contrasted with previous findings and, finally, new results emerged. This chapter will begin with a summary of the results followed by a discussion of the findings while reflecting upon the objectives of the study. A more in-depth discussion about the future implications of the results will be made in the next chapter.

10.2 Summary of results

The current study found a number of results, the most important of which are presented in a bullet point summary below.

The systematic literature search in people with SCI found that:

- There is insufficient evidence in the literature about CMSKP, CBP and CLBP presence in SCI;
- Prevalence of CMSKP is 38% (95% CI 33%, 42%) (among people with pain, this increases to 49% (95% CI 44%, 55%));
- Prevalence of CBP is 37% (95% CI 34%, 40%) (among people with pain, this increases to 47% (95% CI 43%, 50%));
- Prevalence of CLBP is 37% (95% CI 33%, 42%) (among people with pain, this increases to 49% (95% CI 44%, 55%)).

In addition, the general literature review showed that:

- Some evidence about pain and QoL in SCI exists. However, the impact of the experience of specific types of pain, like LBP, on QoL is not examined;
- Functional reduction due to pain presence in SCI has been looked at, often by using assessment scales that were not specific to function in SCI;
- Many studies select participants based on the cause of injury and not the completeness of injury;
- The onset of pain post SCI has been given little attention, in particular, its relation to function and QoL;
- Cross-national studies in SCI, which simultaneously collect and analyse data, are inadequate.

The self-completed survey conducted in the study produced the following results:

- GR-SCIM III and SCIM III have internal consistency of α=0.78. Concurrent validity for "self-care" between GR-SCIM III and EQ-5D is ρ=-0.78 and SCIM III and EQ-5D is ρ=-0.75. Concurrent validity for "mobility" between GR-SCIM III and EQ-5D is ρ=-0.58 and SCIM III and EQ-5D is ρ=-0.45;
- Lifetime prevalence of pain post iSCI is 91.3% (95% CI 86%, 94%). Prevalence of current LBP is 67.9% (95% CI 61%, 73%). Lifetime prevalence of LBP post iSCI is 73.5% (95% CI 68%, 78%). Prevalence of MSKP post iSCI is 38.8% (95% CI 32%, 45%). There is no significant difference in the prevalence of LBP post iSCI between the national groups;
- The mean health index (*classification* of health status) is 0.4±0.3 and there is no significant difference between the countries. The mean *perceived* health status is 62.9±22.5. Greeks perceive their health status to be significantly lower than those from the USA;
- The mean functional independence score is 65.5±20.6 and there are no significant differences between the three national groups;

- The impact of MSKP is greater in women than men. More people with paraplegia report LBP than those with tetraplegia. They also report worse LBP quality;
- There is a strong positive correlation between MSKP and LBP;
- LBP onset is most common immediately after the injury or within the first year. The earlier the LBP onset, the more persistent LBP is;
- LBP is mainly described as “aching” followed by “tiring-exhausting”;
- Quality of LBP is of moderate severity;
- Intensity of LBP is at a moderate level;
- LBP has a stronger negative relationship with QoL compared to MSKP or pain in general;
- The presence of all examined pain categories affects people’s *perception* of their health status more than their *classification* of their health status;
- Worse quality and increased intensity of LBP correlate with worse QoL;
- Correlations between the pain categories and function are, in general, weak.

10.3 Discussion of thesis procedure and findings

The study had one core aim and seven objectives. Some of these objectives were answered via the literature review and others using data collected from the survey. The statistical analysis tested 13 hypotheses which were part of three themes. These hypotheses were tested for the whole group and across nations.

10.3.1 Literature background

An examination of the literature, as in any research, is the first step taken in order to explore the information available which guides researchers through the development

of their own work. This was the route followed in the current project. The literature was examined for pain, QoL and function.

10.3.1.1 Literature on pain

Looking back at the history of pain it was observed that the need to understand pain has been expressed for many centuries conveying the necessity of identifying effective ways to combat this unpleasant feeling. Studying the experience of pain has been a challenge for researchers but progress, though slow at times, has been made. The presence of pain is a major problem for health care systems around the world with very substantial direct and indirect costs.[107,152,280] Pain is a subjective experience affected by many factors and the most efficient way to study it is to look at a specific condition each time and also to focus on pain location and examine influences that may come from other factors like cultural background. Though this idea is not new, it is not often followed.

The purpose of this study was to look particularly at MSKP and pain in the area of the lower back and thus the literature was examined for this reason.

10.3.1.2 Literature on MSKP and LBP

When exploring the literature it was found that despite a wealth of information about pain in general in SCI, information about the specific pain categories examined was very limited. To properly identify the available literature on MSKP and/or LBP in SCI a systematic literature search was conducted. This was the logical step to follow in order to identify the information needed. The advantage of a systematic search is that it uses specific steps and processes that identify and analyse studies published in the literature that may not have been identified with a simple literature search.

10.3.1.3 Systematic review on CMSKP, CBP and CLBP in SCI

An important finding of the systematic review was the lack of evidence on the specific categories of pain examined. The lack of homogeneity among the studies identified made a meta-analysis unreliable and therefore this was not conducted. Dijkers et al[115] could also not conduct a meta-analysis for the same reason. The findings of the

systematic review contribute to knowledge by identifying the mean prevalence and 95% CI for CMSKP, CBP and CLBP reported in the reviewed studies which were high. This review brings to attention the problem of the location of pain in the lower back, something that health professionals are aware of, but it is not studied sufficiently in the published literature. There are increasing calls to improve assessment and conduct subgroup comparisons and the lower back is an area that necessitates further attention.

10.3.1.4 Literature on quality of life and function

Inspection of the literature to explore how QoL and function may be affected when living with SCI, verified the fact that medical and technological advances have changed the lives of people by maintaining life, improving function, if this is impaired, and assisting ADL. In general, recent studies show increased interest in improving QoL in people with SCI often by emphasising the need to reduce pain and improve function in order to achieve this. But examination of the literature did not identify any studies that discussed the impact of LBP on QoL or function in SCI. A clear gap in the literature was noticed.

Brief summary

Drawing upon the theoretical background and the findings of the systematic review, and having examined the first objective of the study, which showed that significant steps forward have been made but more need to be made, the survey design was developed.

10.3.2 The presence of pain, MSKP and LBP

Following the selection of the most appropriate research methods and assessment tools, the most suitable way to conduct the survey was decided. The second objective of the study focused on describing the presence of the categories of pain examined for

the whole group and for each national group and comparing them for differences and similarities.

10.3.2.1 Presence of pain for the whole group

This study found that a very high proportion of people report pain after iSCI (lifetime prevalence 91.3% (95% CI 86%, 94%)). Though this study found a very high prevalence of pain, reports of high prevalence have been made previously,[58,371,380,381,451,489] confirming once more the significance of this problem. One reason why so many people felt pain could be because only people with incomplete injuries participated in this study. People with incomplete SCI have been found to have pain more often than people with complete injuries.[103,317] Another reason could be that more people with pain decided to complete the questionnaire because they felt they had a personal interest in this study. This, of course, can be an issue in any survey study. It is known from the collected non-respondent (drop-out) data that among the 36% of people who dropped out, 34% had pain and only 1.7% did not have pain. But the pain presence for the remaining 64% of people who dropped out of the study is not known.

10.3.2.2 Presence of LBP for the whole group

This study found that there was a high proportion of people with iSCI reporting LBP at any given time point: lifetime post iSCI 73.5% (95%CI 67%, 78%), current 67.9% (95%CI 61%, 73%), last one month 68.4% (95%CI 61%, 74%) and last three months 70.1% (95%CI 63%, 75%). These proportions were higher than expected based on the available literature identified in the systematic review. One could argue that LBP prevalence was higher here than in other reports because more people with pain in general participated, resulting in more of them experiencing LBP as well. However, Raissi et al[371] found a higher percentage of pain in general but a lower percentage of LBP compared to this study. Thus, the above assumption is in doubt.

One other factor, which may have contributed to the higher LBP prevalence, as mentioned previously, could be that only people with incomplete SCI participated. There are no previous reports about people with incomplete injuries reporting LBP more often than those with complete injuries, thus this remains an assumption.

Previous studies reporting on LBP in SCI[318,371,457] reported lower LBP prevalence in their groups but pooled data from people with complete and incomplete injuries when reporting LBP. Other factors, not examined in this study, that require physical assessment or imaging (X-ray or MRI), like the presence of lordosis, which is found in people with incomplete SCI[23] and is known to contribute to the appearance of LBP may have affected the results of the current study. Consequently, the assumption that more people with incomplete SCI could develop LBP needs to be considered further in future investigations. This information could be of importance for health professionals when planning treatment and setting targets for rehabilitation.

Finally, it is not possible to exclude the fact that the recruiting methods followed here, (i.e. no use of random selection approaches) did not result in more people with LBP and iSCI completing the survey because of special interest. Having said this, not many studies in the SCI and pain literature have used random selection techniques to identify their survey participants.

Pain is a subjective experience and despite this current study not being able to or intended to discuss causality of LBP, it can confirm its high presence. The fact that the reported LBP prevalence in the current group is higher than that found in the general population[220,248,263,346] could be because there is greater risk of developing LBP in iSCI.

10.3.2.3 Presence of MSKP for the whole group

The next finding of this study related to the presence of MSKP which was equally high (39%) as revealed in the studies reviewed in the systematic search, where three[19,381,406] of the four studies[19,58,381,406] under review used physical examination or explained the questions to the participants over the telephone in contrast to the current survey in which MSKP presence relied solely on self-report.

10.3.2.4 Presence of the pain categories for each national group and group differences

Among the three participating countries, the Greeks reported pain significantly less often. One reason for this could be differences in the characteristics of the injury itself, as more Greeks suffered from a non-traumatic injury. In another study conducted in Greece[121] pain prevalence was also lower than in the USA[380,451] or UK.[374] Greeks did

not report a different percentage of LBP or MSKP than people from the USA or the UK in this study; therefore, it could be due to cultural factors that Greeks report less general pain. It may be that unless the type of pain is specified (like MSKP or LBP), some Greeks may not consider they are in pain or, alternatively, they do not seek help or report their pain. This may reflect, on the one hand, reduced report of pain by the Greek patients themselves or, on the other hand, reduced assessment of general pain by health professionals. As both these factors could become barriers to the rehabilitation of the patient, these issues need to be examined further.

Another factor which may need to be taken into consideration, when trying to explain pain differences within the national groups, is the possible climatic effect on pain and the different prevailing climatic conditions between the three countries. Some studies have indicated that the weather may affect pain sensitivity or pain perception[175,225,] though the belief that pain is improved when living in a better climate has proved inconclusive.[225] The first population-based epidemiological study to examine the relationship between pain and weather in the UK found that people reported significantly less pain (any pain and chronic widespread pain) on days when the temperature and the sunshine were highest.[276] Similarly, the SCI population living in a hotter and sunnier country, like Greece, may suffer less from pain in general. Further analysis will be needed to address this assumption. Understanding how much and in what ways the environment can affect the experience of pain will also help us understand the dimensions of pain better.

Despite some differences in the demographic profiles and injury characteristics of the groups from the three nations, particularly the Greek group, LBP presence is a significant problem, equally high, for all people in the countries investigated. Similarly, all three national groups reported no significantly different prevalence of MSKP, people from the UK reporting it slightly more often. Often when results were not of statistical significance, particularly in the within- and between-groups analysis, they were of practical significance. The inability to identify statistical significance at times may have been due to the small-sized groups, thus practical significance was used allowing comparisons and enabling discussion of results which would have been

dismissed if statistical significance only was taken into consideration. The similarities in the presence of LBP and MSKP across nations show that international guidelines to address this problem can be implemented but consideration to the effect sizes must given.

In the literature, LBP has often been attributed to be musculoskeletal in nature and this study has tried to examine this via examining the correlation between LBP and MSKP.

10.3.2.5 The association between LBP and MSKP

A positive highly significant correlation between LBP and MSKP pain was found. Taking into account the literature which shows that people with SCI have conditions that can be risk factors for mechanical LBP,[23,100,159,209,287,401] this may be an indication that pain in the lower back is of MSKP origin. However, it cannot be claimed as a causal effect. This association is important both for the clinician and for the patient as it affects treatment of pain[56] or response to treatment[487] which can differ if pain is of neuropathic or nociceptive origin. Therefore there is a need for a multi-professional approach to diagnosis and treatment. People from different professions, including doctors, radiologists, physiotherapists, psychologists and others, may be required to do a holistic diagnosis of LBP. As such, the treatment of LBP may need to involve more than one health professional to deal with the multiplicity of factors that are involved in the continuation of pain. Doctors may have to address pain via medication or other means, but pain specialists or CBT therapists may have to address the cognitive dimension of pain. In addition, physiotherapists will have to work with the patient on, for example, strengthening of the area. A multi-professional team will aim to rehabilitate LBP more efficiently and possibly faster, educating the patient on long-term pain control.

10.3.2.6 Presence of the pain categories and group profile characteristics

This study found that only a few of the demographic or injury profile characteristics affected the presence of pain.

Differences in the presence of the pain categories by gender

Males and females were compared because it is recommended to conduct such comparisons when examining pain.[177] This study failed to find any significant differences for the prevalence of pain, MSKP or LBP between men and women for the whole group. However, one interesting finding was that males from Greece reported significantly less frequent pain than males from the other two countries, which was not the case among females. This may be due to the social role expectations believed to affect men, which may be more prominent within the Greek male population. However, such a difference was not noticed in the case of LBP presence. This could be because LBP is a more disabling type of pain that affects people equally and gender may be irrelevant when reporting this type of pain in iSCI. In addition, as mentioned earlier, people may pay more attention when pain becomes specific. This study cannot support the claim by Greenspan et al[177] about examining pain separately in men and women when the *presence* of pain, MSKP or LBP is considered but in cross national designs it may be an interesting variable to study. In addition the number of areas with pain (pain extent) is worth studying separately in men and women.

Differences in the presence of the pain categories by cause of injury

This study showed that the proportion of people with a non-traumatic iSCI reporting LBP was higher than those with a traumatic injury. Often the literature that focuses on examining SCI includes only participants with a traumatic injury which may lead to insufficient study of the pain categories that may be more common in non-traumatic SCI. Those individuals with a non-traumatic injury are a significant proportion of the SCI population.[296] Therefore, it is essential that they are included in studies and analysed as a subgroup.

Differences in the presence of the pain categories by level of injury

A third significant finding from subgroup analysis, showed that people with paraplegia report LBP and pain in general more often than people with tetraplegia. The presence of pain by the level of injury has been a matter of debate in the literature as, on the one hand, people with lower-level injuries have an increased risk of pain[317] but, on the

other hand, no such differences have been found.[12,374,407,451] However, there is no previous information about the presence of LBP by the level of injury in iSCI alone.

Both the cause and the level of injury could be part of a multifactorial model analysis aiming to determine the characteristics of people with iSCI who may develop LBP. This will be discussed in the next chapter. This study did not find any differences in the presence of LBP, pain or MSKP based on age, or time since injury for the whole group or within the national groups though a tendency for increased MSKP following longer time since injury was noticed. It should be noted that the literature often attributes the variations found for the presence of pain to the variation in the pain classifications used.

10.3.2.7 Classification of pain

The current study did not use a specific classification system to categorise pain. However, information was collected for the categories of neuropathic pain above-, at-, and below-level of injury, MSKP, upper limb pain and back pain. The presence of visceral pain (pain usually located at the thorax or the abdomen[483]) was not directly asked but the information collected via the body chart may suggest its presence. But physical examination, or at least an interview, would have been required to accurately classify pain. Although at the time of designing this study, there were many classification systems available, most did not include pain in the lower back within their categories. The ISCIPDS:B[483] which was published after the start of this study recommends assessing pain location when collecting data clinically. An extended ISCIPDS:E version which will be used in research,[483] but is not yet available, may help researchers resolve some of the problems faced in data collection methods followed in surveys.

10.3.2.8 Persistence and onset of pain or LBP post iSCI

The onset and the persistence of pain and LBP were examined in detail because it has been suspected that they may play an important role in the experience of pain and consequently QoL and function. Indeed it was found that both pain and LBP appeared early after iSCI and their early onset correlated with more persistent pain or LBP. The

current findings agree with reports on the persistence of pain in SCI[90,484,488] or early pain onset[19,240,317,374,484] and add that this is no different in the case of LBP. It is important for clinicians to know that LBP may start early post iSCI in order to assess it early, consider LBP prevention and management techniques including patient education. In this study, no questions were asked about the onset of pain in other areas like the hip or the upper back or the time of the onset of psychosocial factors like anxiety and depression. Future studies should include the examination of the potential risk factors for the onset of LBP or pain following iSCI.

Brief summary

The information gathered to answer the second objective of the study has filled in some of the gaps identified in the literature search, by providing more evidence on LBP and MSKP. Awareness of the problem of LBP in iSCI and acknowledging its significance, will lead therapists to include it in their routine assessments and provide appropriate therapy in a timely manner.

10.3.3 Quality and intensity of LBP

This study is the first to investigate the quality and intensity of LBP in iSCI using the SF-MPQ. Using methods to overcome the technical problems encountered, the third objective of the study was investigated.

10.3.3.1 Intensity and quality of LBP for the whole group

Participants reported a moderate intensity of LBP which remained relatively stable over time (three months) and was characterised as “discomforting”. This finding confirms the single previous report on LBP intensity in SCI which was of a slightly higher moderate level.[457] For people with paraplegia the intensity of LBP was higher, though not significantly so, which is in agreement with Ullrich et al.[457] It is important to study the intensity of pain as it helps health professionals understand what type of treatment may be needed and if it is effective.[43] Though there is no other study that

describes LBP quality in iSCI, the mean PRI did not differ a lot from that found by Cardenas et al[58] for mechanical spinal pain$_{40}$ in SCI. Likewise, it did not differ from the LBP description in the general population.[333] Participants in the current study primarily used the word "aching", a sensory descriptor, followed by "tiring-exhausting", an affective descriptor. These are the most frequently used descriptors for mechanical spinal pain.[58] Using verbal descriptors helps classify pain and "aching" is often used when describing back pain[90] or MSKP[406,483] in SCI or LBP in the general population.[29] Thus, the current description of LBP may be another indication of the musculoskeletal origin of the pain felt in the lower back area, bearing in mind that verbal descriptors and the positive relationship between LBP and MSKP presence (discussed earlier) alone are not enough to classify pain and assessment should include additional forms of examination.

10.3.3.2 Intensity and quality of LBP for each national group and group differences

Overall, people from all three countries described the quality and intensity of their LBP similarly. This shows that LBP as an experience in iSCI affects people similarly despite any sociocultural differences; thus similar clinical pathways for rehabilitation could be implemented across nations. However, two differences may be worth noting; respondents from the UK reported worse LBP quality and intensity, and Greeks used fewer words to describe a similar LBP quality. The latter may be affected by cultural influences as Greeks were found elsewhere to use fewer descriptors to portray their pain.[324] People from the UK who reported worse quality and intensity of LBP were found to report the highest prevalence of all pain categories. This may be an indication that these people have worse QoL or function as will be discussed later.

10.3.3.3 The impact of pain extent on LBP quality and intensity

This study looked at pain extent and found that when pain was more widespread, people reported worse quality and intensity of LBP. Higher pain intensity, including LBP, has been reported to relate to pain extent[59,254] and this study confirms that this is

[40] Mechanical spinal pain has been referred as one of the two types of MSKP (the other one is overuse pain) which is pain in the back or neck areas affected by activity and position.[56]

no different in LBP in iSCI. Widespread pain and higher pain intensity in SCI interferes with various aspects of the life of the patient, which will be discussed later in this chapter. Although the difference was not statistically significant, the mean areas of pain for the UK group was higher than the other two groups which could partially explain why people from the UK experience worse LBP. These research results agree with the recommendations of Carnes et al[59] who emphasised the importance of paying more attention to the impact of multi-site pain on various factors including psychological ones and improving the current self-reported measures of multi-site pain assessment.

Subgroup analysis showed that the lower level of injury, the earlier onset of LBP post iSCI and the increased persistence of LBP all related significantly with worse quality and intensity of LBP. These possible predictors of poorer QoL and function need further investigation.

Brief summary

This study has, until now, provided the information that a high proportion of people with iSCI have LBP, which can have an early onset post injury, be of moderate intensity and often be persistent with no regular breaks. These results justify the intention to investigate this location of pain further, as well as how it affects other aspects of patients' lives. The focus of the remaining objectives was to investigate some of these relationships.

10.3.4 Quality of life in people with incomplete spinal cord injury

Examination of the literature clearly demonstrated the increasing interest by health researchers on the factors that affect QoL, particularly as life expectancy is increasing following conditions such as SCI, with the aim of improving QoL. Using the EQ-5D assessment measure, data were collected and analysed without difficulty and this is discussed below.

10.3.4.1 Quality of life for the whole group

As anticipated, people with iSCI have problems with various aspects of their QoL. This study found a higher proportion of people reported problems with "anxiety/depression" compared to reports in the literature.[126,188,253] One reason that could explain this is the presence of the Greek group which has not been included in other reports in the SCI literature and which, in the current study, reported more cases of "anxiety/depression" than the other two national groups. For the whole group the mean index for *classification* of health state was 0.4±0.3 (mean±SD) and the mean score for *perceived* self-rated health was 62.9±22.5 (mean±SD). Both these scores show what appears to be a moderately good level of QoL, despite the presence of the disability, reported by the respondents. Although this may seem strange, this has been reported previously.[6]

This study found no significant differences in the reported QoL between men and women and no correlation between time since injury and QoL. It also found that age associates with a decline in the perception of self-rated health. All these findings have been previously reported.[313,349,362] Finally, this study cannot confirm previous reports that people with paraplegia have significantly better QoL that those with tetraplegia.[313] A future study to analyse data solely from people with iSCI will be needed in order to further validate the findings of the current study.

10.3.4.2 Quality of life for each national group and group differences

It was mentioned above that Greeks reported more cases of "anxiety/depression". Greeks have been found to report higher anxiety prevalence than people from the UK[290] and older Greeks to have higher levels of depression than younger ones.[467] The Greek group in this study was significantly older than the other two groups which may explain this finding. Another finding is that Greeks also perceived their self-rated health as worse than people from the other countries despite their health state classification not being significantly worse. This finding cannot be attributed to gender, sometimes reported to affect QoL, as the proportion of males and females between the countries did not differ. However, age could have affected this result as the Greeks were older and increased age relates to a decline in *perceived* health.[349] Yet, people

from the UK, who were significantly older than people from the USA, did not report worse levels of "anxiety/depression" or QoL. What could have affected this result is the fact that the non-Greek groups replied mainly online and people using the internet are found to have better self-rated health.[85] Nonetheless, studies on QoL of the general population do not report great differences between a Greek group[247] and a USA group,[274] but when people with a health problem were looked at, Greeks *perceived* their health status as worse.[319] Therefore, it is possible that the impact of culture on health perception is greater when health is disturbed. Alternatively, the health service provided differs affecting perception of health status, but these factors alone do not explain why the health index remains the same.

In Greece, in 2001, new legislation was published aiming to implement integrated primary health care (PHC) but this is yet to be achieved.[268] While community health centres could be suitable in the current Greek setting,[268] the medically-orientated Greek health system, though being specialist orientated, may still be too "inflexible" to accept changes essential for long-term rehabilitation. There is a lack of SCI units in Greece leading, to people being admitted to general hospitals after their injury,[120,356] with possible negative consequences for the complications that can follow SCI in the later stages,[120,356] thus increasing the level of anxiety patients feel and their perception of QoL. There is a need to examine the impact of the health care system on the QoL of people with SCI living in Greece and compare it with Greeks living abroad under different health care systems. The findings may have implications both for the rehabilitation of Greeks living in Greece but also for those outside, for if the perception of QoL is more affected by culture, then health professionals in the UK and USA, where large Greek communities live, will need to consider this in their treatment plans. Over the last few years private rehabilitation centres have opened in Greece and people with SCI may (or may not) receive public funds to attend them. Outcomes from such centres need to be included in future studies.

Finally, two findings emerged when health status was examined by the demographic and injury profiles of the respondents. The first was that a significant interaction effect between gender and country of residence on the health index existed but two-way

ANOVA did not reveal which groups differed. The inability to identify the exact effect may be because the difference was too small to be detected or that larger-sized groups were needed to detect differences. Another finding was that the cause of injury and the country of residence interact significantly with perceived health status. These two findings will need to be tested further as both are helpful in understanding what SCI and demographic features may affect QoL cross-nationally.

10.3.5 Function in people with incomplete spinal cord injury

A reduction in function is the primary complication following SCI and a number of factors that influence function have been examined in the literature. Using SCIM III, data were collected with no difficulties. This study is the first to have translated SCIM III into Greek and the first to have used SCIM III as a self-completed measure. The implications of this will be discussed in the next chapter. The fifth objective was to describe the function of the group.

10.3.5.1 Function for the whole group

As expected, the participants had reduced function but overall they maintained a good level of functional independence possibly more than reported in other studies in the SCI literature. This is probably explained by the fact that only people with incomplete injuries were included.

10.3.5.2 Function for each national group and group differences

This study found that Greeks scored the best mean function of the three groups and people from the UK reported significantly lower mean function than both the other groups. Earlier, it was seen that people from the UK have the worst experience of pain and report a worse health status. In addition, they also report worse function. It can be seen that there are connections between these three areas but no causal effects can be assumed.

The subgroup analysis examining the demographic and injury profile characteristics revealed a finding that was not expected; for Greeks, older age (when time since injury

was controlled for) correlated with better function and, on one occasion, it reached significance level. This contrast with both the direction of the correlations found for the rest of the group and also reports in the literature.[266,446] Factors including more or less family support or different expectations from functional abilities with increasing age may have contributed to this finding. This area needs further investigation.

Brief summary

Objectives four and five have described both QoL and function in iSCI. Some of the findings confirmed previously known information while others have added new. Three major areas of concern for a person living with an iSCI; pain, QoL and function have so far been described and the next logical step was to investigate how they interact with each other. The final two objectives were set to do so.

10.3.6 The impact of the presence of pain on quality of life and function

No significant difficulties were noticed when the measures to collect data were cross-analysed. To this author's knowledge, this is the first study to report on the possible impact of LBP on QoL and function in iSCI and the first to discuss the impact of any type of pain on QoL and function in iSCI in Greece. The findings are discussed below.

10.3.6.1 Pain presence and quality of life for the whole group

This study found that a high proportion of people with iSCI and pain, MSKP or LBP were "anxious/depressed". This was a result to be expected as the literature supports this finding. What is of importance to note is the conclusion that LBP has a greater negative effect than MSKP or pain in general on what people perceive as being a good health status. Lack of research into LBP in SCI may mirror a lack of attention to this problem and a possible lack of early management, perhaps resulting in people perceiving it as a greater challenge for a good QoL. Putting these variables into a multiple regression model will help to understand further the importance of each type of pain on QoL. The negative impact of LBP on health status was also confirmed as the more LBP days felt

in a month, the lower the health status, confirming once more the need to understand why and when LBP may become chronic and more persistent.

10.3.6.2 Pain presence and quality of life for each national group and group differences

It was found that although the QoL of people from all three groups was similar, for those from the USA, QoL was worse when LBP worsened further and when its persistence increased in comparison to the other two national groups. In addition, the later the LBP onset, post iSCI, the better the health status for the same group. It may have been that the Greek and UK groups were not large enough in number to capture a significant result as the direction of the correlation was the same for these groups too, although in most cases the strength of the correlation was not as strong. However, this may be a consequence of a societal belief in America that pain is bad and needs to be quickly eliminated,[328] which may result in perceiving worsening of pain as a greater "threat" to QoL. This belief may be less important in non-American societies, though it should be noted that the three countries examined share many similarities.

The experience of pain, overall, affects the health status of people with iSCI very similarly, irrespective of differences in injury and demographic characteristics. Again, what seems to be of more importance is the type of pain which has a different impact on health. In this case some gender-related differences were found as women who suffered from MSKP perceived their health to be worse than those who did not suffer from this type of pain. This was not noticeable in males. In contrast to the above findings, the impact of MSKP on health for the UK group was larger for males than females and though there were no significant differences, the effect sizes were larger indicating the practical significance of the result. In addition, for the Greek group, within males those with MSKP *classified* their health state as worse than those without MSKP, but their *perception* of their self-rated health did not seem to be as affected. This was not the case among Greek females. The conflicting findings with regard to pain differences between males and females have been reported in the literature along with reports that the intensity of pain can affect QoL. This study did not examine intensity of MSKP and how this may affect QoL differently between men and women.

Taking into account the question posed by Greenspan et al[177] as to whether assessment measures should include gender-specific questions when examining people, and in light of the evidence found here this may be the case for MSKP. In particular, the ISCIPDS:B_{41} uses some items from the MPI_{42} to examine pain interference including interference with mood. Among the types of pain examined in the data set is MSKP. It may be helpful to add a question related to health status perception as this may differ between and within genders in a single nation or across nations. This may be particularly useful for clinicians in multicultural societies who may need to differentiate treatment options for their patients.

10.3.6.3 Pain presence and function for the whole group, each national group and group differences

This study found that the proportion of people reporting worse function when the categories of pain were present was, surprisingly, not large. On the contrary, people with pain, MSKP or LBP reported slightly better function than people without these categories of pain though the differences were not statistically significant. This was noticed within each national group too. This finding contrasts with other findings in the literature both from the SCI population[362] and the general population, including the elderly.[94,496,498] Function was not greatly affected by increased persistence of pain/LBP or earlier pain/LBP onset post iSCI, though the latter had a stronger correlation and was of an opposite direction within the Greek group. Future studies could examine if older age is a factor affecting this result.

Though many of the features investigated in this study have not been investigated in a similar way in previous studies, it was unexpected to find that a number of variables did not relate with worse function when they have already been found to relate with worse QoL. A number of reasons may have contributed to this result. First, the type of injury the participants had. Had the study pooled together people with complete and incomplete injuries, as often happens in published studies, the result may have been different.

[41] International Spinal Cord Injury Pain Basic Data Set.[175]
[42] Multidimensional Pain Inventory.

Another reason could be that people become more 'determined' to be functionally independent irrespective of the presence of pain. Also, for some people the need to 'get rid of' the pain may become a motivation itself and they use activity to do so. These may contradict the theory of pain-fear avoidance which is based on avoiding, due to fear, movements or activities that may increase pain or cause (re)injury and result in functional reduction.[51,468] The impact of chronic pain on everyday physical activity may be relatively small[458] and Hammell[186] argued that people with an impairment, like SCI, are reported to change their perception of 'self-worth' and try to find things they can do.[186] A number of other factors that have not been examined in this study could have contributed to this finding, for example, SCI self-efficacy which has a positive association with function,[331] behavioural and social factors such as the level of family support when the person with iSCI is in pain. As the experience of SCI is a continuous learning process,[61,109] people in pain may intentionally seek to be more physically active in order to maintain good health. Having an incomplete injury may help them to achieve this goal more easily than those with a complete injury. Conclusions cannot be drawn as these issues were not examined in the current study but they are interesting phenomena.

To summarise, this study showed that people function relatively well across countries despite their pain. Future studies and clinicians need to consider what the reasons are for the increased motivation towards functional independence for people with iSCI. Identifying such motives for positive behaviour is more likely to enhance therapeutic outcomes. It is widely recommended in various guidelines[5,54,325,461] that remaining active is one of the most promising approaches to treat non-specific LBP especially in early stages and thus decrease the likelihood of its chronicity. The combination of physical and psychological treatment programmes with the inclusion of CBT approaches is also encouraged.[325] The CBT model is based on the assumption that pain and disability are influenced by somatic and psychosocial factors, and uses methods to change cognition and thus minimise negative behaviour.[360,462] Finally, further studies will need to use SCIM III and GR-SCIM III, under the same or similar conditions as used here, to ensure that the findings are not attributable to the psychogenic properties of the measure.

10.3.7 The impact of low back pain quality and intensity on quality of life and function

The final objective of the study was to examine how QoL and function relate to the quality and intensity of LBP. The main findings are discussed below.

10.3.7.1 Low back pain quality and intensity in relation to quality of life

This study showed that poor quality and high intensity of LBP negatively relate to QoL and that the relationship is stronger when LBP intensity is involved. This is the first study to confirm this in iSCI. It is known from the literature that increased pain intensity negatively affects QoL in SCI[313] and in other situations including cancer,[478] adolescence[219] and women with LBP.[439] It is important to understand that LBP, which is commonly reported in iSCI as shown here, interferes with health and this is a characteristic noticed across each national group examined. When LBP becomes more constant and the LBP-free periods are reduced, LBP intensity increases, thus therapists need to consider earlier interventions to avoid LBP becoming chronic and constant which eventually will affect QoL.

10.3.7.2 Low back pain quality and intensity in relation to function

Earlier it was discussed that the *presence* of LBP does not significantly affect function; however, increased LBP *intensity* negatively relates to function, which is significant particularly for "mobility indoors and outdoors". This was noticed across the three countries, particularly for people from the UK for whom the experience of pain is more severe. People with SCI who report higher pain intensity levels also report greater catastrophising, psychological distress and pain interference.[450] Therefore, it is important to assess intensity of LBP as this may be the characteristic of LBP which interferes more with worsening of function. Since increased LBP intensity is a limiting factor particularly for "mobility indoors and outdoors", it is likely to impact negatively on socialising, social participation, employment and even life satisfaction, which are all necessary for a good QoL. Reflecting back on the existing guidelines for treating LBP, it is important that multi-approach rehabilitation programmes promoting function start early.

10.4 Summary of major issues related to pain in iSCI

The issues found in this study to relate to pain in iSCI can be grouped into three areas; 1) SCI features, 2) demographic profile characteristics, and 3) category of pain. The first and the last groups are found to be of more importance to the experience of pain.

The completeness of injury is one of the SCI features that needs to be considered when studying pain in SCI. Incomplete injury may be the reason that explains the high prevalence of pain in this present group, making people with iSCI more vulnerable to developing and reporting pain. This may be more significant in the case of LBP. The cause of injury is another SCI feature of importance to be examined when addressing LBP in SCI, as this study showed that people with non-traumatic injury report LBP more often than those with a traumatic injury. In addition, the cause of injury in combination with the completeness of injury may explain or predict earlier onset of LBP. Finally, the level of injury is the last SCI-related feature that needs to be taken into consideration when studying presence and intensity of LBP. This study does not confirm previous reports that people with lower level injuries enjoy a better QoL. It actually found that people with tetraplegia perceive their health status as better compared to those with paraplegia though the difference was not statistically significant. This is another indication that the completeness of the injury is of great significance in determining how the experience of living with SCI may be affected. Of course, incomplete injury cannot solely account for better QoL as multiple psychosocial factors may affect it. Finally, the level of injury was a feature determining better function. As the SCI-related features are in general known from the start of the injury the clinicians can pay early attention to those found to affect the experience of SCI and pain.

This study found that the demographic profile characteristics of people with iSCI may not be particularly important in the presentation and experience of pain, though factors related to MSKP do seem to differ for males and females.

The final issue to be considered in relation to pain in iSCI is the type of pain. This study found that LBP in iSCI is a more disabling category of pain. Future studies need to

address if LBP can be so disabling that it leads people to overcome their cultural influences, in some cultures, or whether it is because of sociocultural reasons that LBP is reported more often. The results of this investigation may indicate different treatment approaches. Disabling LBP may need medical or physiotherapy techniques to be used, but increased reporting due to sociocultural reasons may need to be focused on social and cognitive approaches.

When LBP is present, it is important to assess how patients' sensory, affective and cognitive dimensions are affected, given that LBP can have such a negative effect on people's perception of QoL. The similarities across nations in sensory, affective and cognitive dimensions may be an indication that there is a biological or biopsychological mechanism[177] of LBP in iSCI that needs further research and investigation.

Having discussed the increased likelihood that a person with SCI may report more than one site of pain, which is linked here with increased severity of LBP, it is essential to use tools like the SF-MPQ to assess more than one type of pain. In non-clinical research settings it is often difficult to assess each single pain site, thus asking the patient to focus on the most important ones can be preferable. In clinical and rehabilitation settings it may be easier to assess more pain sites while the patient is present.

Chapter 11; Discussion of future implications

Chapter Brief Table of Contents

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"It is not pain that is to be dreaded, but the fear of pain"

Epictetus (AD55 – AD135), Greek philosopher

11.1 Introduction

The previous chapter focused on a discussion of the results in relation to the study's objectives while reflecting back to the literature. This chapter will focus on a more in-depth discussion about the future implications of the results and how they fit in with current models of rehabilitation or assessment. This discussion will progress via reflecting upon the original contributions, strengths and limitations of the study and will propose changes that could be applied in light of the evidence.

This chapter will start with a discussion of the radical changes that have occurred over the past few decades which have led to the development of different treatment approaches that have shifted rehabilitation in both pain management and SCI from a doctor-centred approach to the active involvement of the patient in the planning of programmes. It will then finish with future recommendations.

11.2 Pain, disability and related models

Our current knowledge of the experience of pain, namely, the complex theory of neuromatrix, which puts the unidimensional beliefs and knowledge of previous pain theories under one multidimensional "umbrella", has led to the development of new treatment models and pathways. Today, the biopsychosocial model of chronic pain is the most widely accepted model of understanding and treating pain.[163] This model pays great attention to both disease and illness with the second being the subjective experience of the symptoms of the first.[163] Building upon the theories of Melzack for the body-self neuromatrix which integrates the sensory-discriminative, motivational-affective and cognitive-evaluative components in the experience of pain, researchers have been trying to explain the "bio" part of the biopsychosocial model by using modern technology (e.g. genetics, electrophysiology and brain imaging).[163] The interaction of the dimensions of pain has driven the need to search for further answers in the "psychosocial" part of the biopsychosocial model. The affective component of pain interacts widely with the

emotions that it creates which tend to be negative.[163] The most extensively studied emotions have been depression and anxiety, often included in scales to measure QoL like the EQ-5D scale used in this study. There are other such emotions that have received less attention, for example, anger and emotional distress which can be directed towards the health service, the health professional, or family members and generate hostility and resentment.[163] Patients have expressed frustration towards health professionals for their lack of understanding of the secondary complications of SCI.[109] Considering LPB as a possible complication following SCI, early discussion about it could help patients and their families to be more prepared. All these emotions interact with each other over time and they interact with how the person in pain perceives it cognitively.[163] A number of such cognitions have been studied including appraisal and beliefs, catastrophising and fear-avoidance, perceived control, self-efficacy, vulnerability and resilience.[163] Gatcher et al[163] correctly point out that though these negative factors, which can be predisposing and perpetuating factors for the experience of pain, have been extensively studied lately, there is little evidence on the protective factors of pain and disability. Such factors can include hope and optimism.[163] Patients themselves express the need for more focus on their abilities and strengths[109] and they use cognitive and behavioural strategies to increase their motivation to promote physical activity.[242]

This huge interaction of factors in the experience of pain and disability, some of which have been mentioned in this thesis, have led to the need for an interdisciplinary pain management approach which should include a complete assessment and treatment of the dimensions of pain with the aim of making treatment more effective.[162,163] Recent treatment approaches include tailored treatments such as the graded exposure to fear-avoidance beliefs, patient education and CBT. Such interdisciplinary models of treatment illustrate the clear need for more active participation of the patient in his/her care. As such the “patient-centred” and the “expert patient” models have been developing rapidly.

In SCI, the philosophy of research has been changing from “cure” to “care” over the past few decades, mostly due to the work of the SCI model systems (SCIMS) introduced in the

1970s in the USA.[258,437] Treatment is now directed towards preserving the functions of the body that are necessary to preserve the independence of the individual.[437] To achieve this there have been technological advances (assistive technology) but also methods to improve psychosocial outcomes.[437] The WHO has developed the International Classification of Impairment and Disability (ICF) that takes account of environmental and personal constructs.[73,437] Recently, the "ICF core sets for people with SCI in the long-term context" were developed, and back pain is one of the constructs that can limit function and health in SCI.[73] Clearly the purpose of the current study to examine LBP in more detail is justifiable. Although the ICF core sets in SCI explain what should be examined they do not explain how, something the ISCIDS could work on.[73]

The achievement of independence is done via rehabilitation. The necessity for health professionals to see SCI from the perspective of the patient and understand that rehabilitation is a dynamic learning experience that entails long-term adjustment strategies has been pointed out.[61] Carpenter[61] said that patients themselves want health professionals to overcome stereotypes and assumptions about a person's injury and involve the patient, who eventually becomes the most experienced in their new condition, in their treatment planning. Clearly, what emerges from this report is that continuing education of both patients and health professionals is essential. Similar opinions on this matter have also been summarised more recently in the review by Gatchell et al[163] who said that some health professionals may have beliefs themselves about fear-avoidance which may affect how they devise and recommend treatment.

These voices that have been raised over the past few years led to the development of the Stanford Chronic Disease Self-Management Program (CDSMP), which was a lay-led self-management course created in the USA back in the 1970s.[178,494] This programme has been adopted and adapted in the UK as the "expert patient" programme, which has been promoted by the DoH since 2001.[106,191,453] The model of the "expert patient" is based on the concept that, in the UK, the predominant disease pattern is chronic rather than acute.[106] Having as its primary aim the improvement of the patient's QoL by modes of

reducing the severity of the disease, decreasing the speed of deterioration, decreasing pain, while increasing self-esteem and keeping patients stable, this creates a partnership between the patient and the health professional where decisions about the management of the disease are shared.[106,191] In this model the health professional maintains the medical knowledge, conducts diagnosis and prescribes accurately, while the patient is offered more access to information in order to make informed decisions.[104,189,455] This empowerment of the patient results in an increase in their confidence, and motivates them while giving them choice, voice and control.[106,191,453] In addition, health professionals become more reflective and understand better the expectations that patients may have.[106,191] This model, which is generally well accepted, though it is criticised too,[452] links well to earlier calls to think of the long-term rehabilitation of the patients as Carpenter[61] pointed out. Studies from CDSMP and the "expert patient" programmes have found them to reduce health distress and outpatient visits,[272] while those with lower self-esteem and HRQoL improved more.[375]

The ICF, which promotes the patient-centred goal setting model,[259] includes the concept of "participation" which means being involved, being accepted and having access to resources.[60] As already mentioned, people with SCI say that it is important to them to be physically active[60] and, studies and guidelines suggest that keeping active reduces pain.[5,325,394,461] Therefore, it is essential that functional independence and activity are promoted and patient participation encouraged. As physical health tends to deteriorate when ageing with SCI,[260,438] it becomes important that rehabilitation in the community continues in the long-term enabling patients to adjust to the changes in their physical health.

11.3 Relevance of original contributions to current concepts

The findings of the current study fit with some of the features of the above models which are considered desirable for the future of patient care. Though this study has not

analysed, and does not intend to claim findings related to the rehabilitation and socioeconomic factors that interact with the experience of pain or SCI, it can inform the formulation of proposals for the future.

11.3.1 Implications of the systematic review

The importance of continuing education of health professionals and access to information by patients are central requirements of the new models. The original systematic review on CLBP, CBP and CMSKP in SCI, conducted here, brings the insufficient investigation on these topics to the attention of a wider range of health professionals and directs them to seek out more research on them. The findings of the systematic review can also be accessed by patients themselves (as they will be published) enhancing awareness of both parties of the partnership in the "expert patient" model of rehabilitation.

11.3.2 Positive implications for Greek therapists and researchers

Another contribution of the current study is the translation of the GR-SCIM III into Greek for the first time. This development method used both published protocols for translation[40,300,377,501] and the advice of the original authors of the SCIM III (personal communication). The forward and back-translations were not problematic. The advantage of the method was that all translators were bilingual and had educational achievements to at least tertiary level. The advantage of the back-translation ensured the integrity of the items and, together with the use of an external panel, acted as a check for the preservation of face validity. Due to the small sample size of the Greek respondent group, it was not possible to carry out a full study of validity and reliability. However, the results reported on validity and reliability should be regarded as initial testing of the psychometric properties of GR-SCIM III.

The availability of this measure will have positive implications in the future for the assessment of functional independence for people with SCI in Greece. Systematically collecting, analysing and interpreting data from standardised tools can be done in the clinical setting and become evidence that the rehabilitation followed is effective.[154] Now Greek health professionals can use this function measure in clinical settings, and also policy makers in Greece could include it in their recommendations. Using a standardised assessment tool will also allow comparisons between Greek groups and other groups who have used the English version of SCIM III, enhancing research and assisting therapists to compare their group(s) with other groups in order to follow the best treatment approaches suggested in the wider literature. Explaining to the patient the value of using a widely used and accepted measure could also have a positive impact on the relationship between therapist and patient as the latter could feel that he/she is more accurately assessed and significant attention is paid to treatment planning.

11.3.3 The value of self-report

The next original contribution of this study is the use of SCIM III and GR-SCIM III as self-completed measures for the first time. The validity and reliability of the English version were examined using a large enough sample, similar to or larger than other studies in which other measures were translated and validated.[165,166,244,311,443] Unidimensionality was confirmed and reliability was acceptable for both the English and the Greek versions. Validity was better for the Greek version.

While this study does not imply replacing the function assessment done by the health professional via observation, it provides new and positive implications for the care of the patient in two ways. First of all, it builds on the call made by Dawson et al[96] for the need of a new self-reported measure to assess function in SCI which would represent the patient's perspective. Self-assessment of function may help patients who, according to May et al,[291] want to become self-aware and take responsibility for problem solving. The FIM self-

report measure developed recently provides a measure of perceived functional independence.[286] Although SCIM III, as used here, is not a new self-reported measure but an adaptation of a current measure, it is the first attempt to present the patients' perspective about their function rating while using a SCI-specific measure. The fact that participants in this study managed to complete the scale without problems indicates that function in SCI can be assessed via self-reporting. Future studies may need to include new items in this particular scale, aiming to capture the cognitive aspects of the functional challenges and the behavioural outcomes as perceived by the patient.

The second positive implication of using this self-reported measure links to a realistic structure around long-term rehabilitation. Patients request improvement in long-term rehabilitation,[61] the "expert patient" and CDSMP models promote empowering of the patients, teaching them skill while seeking to reduce the socioeconomic cost of injury and rehabilitation.[106,191,453] The continuous process of rehabilitation requires constant identification of problems that need to be addressed,[421] and patients want to know practical information like for their "bladder & bowel" problems,[291] thus the patients' self-assessment of their function will help them to "keep an eye" on any changes while growing older with SCI. Consequently, they will be able to feed back to their individual therapists or their rehabilitation group with the aim of responding quickly and in an appropriate manner to the changes noticed. While there are numerous course places currently in the UK on "expert patient" programmes, there are no such programmes in Greece. Thus, Greeks may have to rely more on their own individual self-assessment and report to their private health professional if they have one.

11.3.4 The significance of cross-national reports

This study provides some findings that are new to what it is known so far in regard with living with SCI. First, using a single study to compare groups of people from these particular three nations has not been conducted before. The information collected adds to

the minimal information known about SCI in Greece and, in particular, about the perception of the patient of their own experience where pain, QoL and function are concerned. The next step will be to ask patients with SCI in Greece in more detail about the experience of living with SCI. This could be done via in-depth interviews which give better "insider" information[99] or structured face-to-face or telephone interviews.[61,86,109,230,242]

Where LBP in iSCI is concerned, an examination of it in such detail has not been done before. The relevance of LBP by level of injury is a new report, and the quality and intensity of LBP by examining the three dimensions of LBP, as described by Melzack, is carried out for the first time. Linking this information with QoL and function enables a better understanding of the biopsychosocial model of LBP in this population. The findings show that the experience of LBP may be worse than that of pain in general in iSCI and concludes that the importance of LBP in SCI may have been underestimated. This ought to be examined and reported more in the literature and more studies are needed to confirm it. People with SCI who are in pain may be more prone to being caught in a vicious cycle of increased pain, social isolation, inaccessibility and reduced QoL because they may have to overcome more hurdles compared to people with pain but without SCI. Disabling LBP needs to be considered when pain is discussed in SCI.

Finally, another original result of importance is the conclusion that Greeks with iSCI report lower QoL compared to their equivalents from the other two nations. Possible reasons for this finding were discussed in the previous chapter and will not be repeated here. This study provides the first reference document for Greeks with iSCI in regard to their LBP, QoL and function, which health professionals can use and take the research forward. Research in Greece now needs to be tailored towards understanding why Greeks may differ from other groups from countries that developmentally are not dissimilar. The question they need to ask is "how much this effect is a result of the health care system or is it a cultural issue?"

11.4 Strengths of the study and the significance of the findings

This study has a number of advantages that derive from its methodological approach and shows positive implications for the future research directions in SCI.

11.4.1 The power of modern data collection methods

This study is the first to recruit participants and collect data on SCI online while simultaneously studying three countries. The use of modern technology in research and also in clinical patient assessment had been steadily increasing over the past few years. Previously, there have been single-nation studies which used electronic tools (i.e. pain diaries, 2- or 3-D drawings) to collect data from subjects including people with SCI.[167,355,385,463] It may be considered that people with functional difficulties may be limited or even unable to use a computer to complete an online survey; however, there is no strong evidence to support this. On the contrary, computer usage by people with SCI is high[172] (USA statistics). Consequently, the decision to use this method of data collection with this specific group of participants is defensible. Although this methodology still has challenges and limitations, techniques can be used to adjust to the needs of the study. This enables online surveying, which is a tool with immense potential, to be deployed when cross-national designs or large group sizes are desired. Indeed, at the time when this study was recruiting participants, the team of Turk D, Dworkin R and colleagues[129,449] started publishing their work which included a web survey studying pain and they recruited a much larger sample than the one for this study (nearly 1000 participants).[129] Following personal communication with the author (Dworkin R on 13/01/2012), it was reported that some people with SCI were likely to have participated in their web study, however analysis did not reveal this distinct group of patients. Thus, participation and the number of people with SCI completing their web survey[129,449] is not given.

The current study demonstrates that surveying people with a physical disability like SCI can be achieved using online methods. This has multiple implications that can affect the

future of both research and rehabilitation in SCI. First, researchers will benefit as they can design and run studies in SCI with reduced costs and faster data collection, making international studies easier to conduct and facilitating the understanding of the experience of pain in SCI. Moreover, patients across countries can participate in research which empowers them to have their "say" by including them in the process of making general decisions about care and future directions in SCI. Though these benefits for patients participating in research are not unique to online studies, the additional benefit of online research is that this opportunity can be given to a greater number of people many of whom could not participate in a paper survey for various reasons.

Another benefit of an online survey seems to be the possibility of collecting some data on "non-returned" (drop-out) questionnaires as the database holds information on the system for any questionnaire that has been started but not submitted. In this way, the researcher may be able to start exploring the reasons why some people decided not to complete and return the survey. A postal paper survey is unlikely to offer this information unless the researcher has access to some of the non-respondents profile characteristics (e.g. demographic information) which would be difficult if the survey is anonymous. In the current survey there were "non-returned" questionnaires (n=136) in which the people who dropped out completed some questions related to pain. These have not been analysed further, as this was not within the aims of the current project, but they could be considered for possible later analysis.

Usage of online tools can be beneficial for patients' rehabilitation as well. Tele-rehabilitation is a recently suggested method of rehabilitation in SCI, with encouraging early results, where patients give feedback electronically and are monitored via videophone sessions.[93,160] Assessment of function was done using the SCIM by observation before discharge from the SCI unit and again at six months. A home exercise programme was conducted and function for one group improved. Some functional tasks were assessed during the videophone sessions via interview.[93,160] The use of SCIM III by self-reporting, as suggested in the current study, may add to the future benefits of tele-

rehabilitation. In Greece, a similar programme of telemedicine-assisted home support was used for people with pulmonary problems and a decrease in hospitalisations and use of health services was found.[473] As patients have expressed the desire to have a multidisciplinary outreach team to help them adjust in the community,[86] the future of smooth transitions from SCI units or general hospitals (in the case of lack of specialist units) to the community and the monitoring of patients' progress could fall within the remit of online technology. This could potentially help bring health care costs down, which is an ever-present goal of health departments, while maintaining contact with the patient.

11.4.2 Statistical analysis

Another strength of the study that should be mentioned here relates to some of the methods used in the statistical analysis. The study aimed to be descriptive both when presenting differences and correlations between groups. The only exceptions were testing of SCIM III and GR-SCIM III and investigation of the effect of the "country of residence" where methods of factor analysis were used. The chosen analysis was suitable for the purpose of the study but did not rely solely on $NHST_{43}$. Correcting for multiple testing, finding the 95% CI and the effect sizes, which are increasingly a requirement in published literature, enhance the reliability of the results. Often descriptive studies in the literature fail to report these statistical components. Application of the Bonferroni correction resulted in losing some statistically significant results but strengthened those found. A less conservative test, like the Sheffé, could have been used which may have allowed more statistically significant results to have passed the alpha level but these tests are less accurate on reducing Type I error than Bonferroni. Descriptive studies that seek to explore new areas for research need to include in their analysis at least these statistical components.

[43] Null Hypothesis Statistical Testing.

11.5 Reflection upon the study limitations

This study has a number of original contributions and strengths but there are limitations as well, that are often unavoidable in research and some may be out of the control of the researcher. However, they should be acknowledged and discussed, as future researchers may find them informative for their own research purposes.

11.5.1 Length of the questionnaire

It is possible that the length of the questionnaire was a limitation of the study. Though opinions about the importance of the length of the questionnaire differ, it may be true that some people dropped out of the study because of it. Indeed, a number of people started the questionnaire and did not complete it, but they could have done so for a number of reasons other than the length of it. Around 6% of respondents commented on the presentation of the questionnaire and the length of the questionnaire was not among their concerns. The current survey shows that designing a lengthy and possibly complicated online questionnaire, but applying additional measures to outweigh its length, can be enough to give completion rates very similar to postal surveys. This is encouraging, and shows that as both researchers and participants gain more experience in this methodology, completion rates will probably rise.

11.5.2 Non-probability sampling

Non-probability sampling, as used here, can be a limitation in the discussion of generalisability. Furthermore, the fact that not all people with SCI have access to the internet limits generalisability of the results even if random selection sample methods were applied. Though both are acknowledged limitations of the study, they are problems not solely encountered in internet surveys, as a telephone survey may suffer from the same problem because not everyone, for example, is registered in the phone book. Health

professionals in both clinical and research settings should encourage people with SCI to use the internet, which is likely to benefit them as individuals, but also help promote online research. The wider use of the internet is more likely to reduce barriers in the discussion of generalisability.

11.5.3 Generalisability

By comparing the profile characteristics of the participants to those of other studies the discussion of generalisability can be promoted. The current study used community samples which are extensively used in non-online surveys.

While more women participated compared to the majority of non-online studies, this need not be attributed to the online methods because this has been noticed in non-online studies too. It may be that more women with SCI are starting to participate in studies.

The current study found that its participants were injured at a slightly older age and mean age at study was at the upper range of that commonly reported in non-internet studies. But since age at injury is rising,[332] this difference should not be attributed to the online methods.

Participants in the present study had a higher level of education than in other non-online studies[112,299] which may be a result of following online methodology and could possibly contribute to the low missing data found in the completed questionnaires. The participants may not have had difficulty understanding the questions including SCIM III, which uses a terminology that non-health professionals may consider difficult. Then again, the knowledge of SCI-related terminology by people with SCI should not be underestimated. Accessibility and exposure to new technologies could help reduce the educational gap between people who respond to online and non-online studies.

The final difference noticed between the current group and those in previous non-online studies, was the percentage of people who were married which was higher in this study.

This may not necessarily be attributable to the online method but it could be due to other factors such as the presence of more women in the group, the higher level of education of the sample or the incomplete injury, all of which can contribute to a reduced divorce rate in SCI.[42,110] Bearing in mind the differences in the level of education and marital status, the current group has the characteristics of people with SCI who live in the community, thus generalisability of the results may be considered, but with caution.

When considering generalisability of the results from Greece, age may be a limitation. The Greeks were older both at the time of the study and the time of their injury compared to people from the other national groups or studies in the literature. The Greeks were found to be of older age at injury[249] compared to other non-Greek studies but not as old as in the current study. There are not many studies conducted in Greece, either epidemiological or recruited via the community, and the lack of any central SCI registration restricts conclusions as to whether the current Greek group is similar to the general community SCI population in Greece. While it cannot be conclusive which factor affected this finding, generalisability of the results when discussing iSCI in Greece alone cannot be assumed. This constitutes another reason why further investigation of SCI in Greece is necessary as, in order to implement clinical pathways for assessment and rehabilitation that are found to be effective in other countries, an understanding of the differences or similarities in the profile characteristics of the groups must be established.

11.5.4 Self-completed questionnaires

The self-completed questionnaire is a very common technique used in survey methods but it imposes a number of limitations. One of them is that it cannot be guaranteed that the questionnaires were indeed completed by people with SCI even though there is no reason to believe otherwise. While only a small percentage of people did not know the completeness of their injury, the lack of a physical examination or access to medical records to confirm the ASIA level of injury may be another limitation of the study. While

there are limitations to self-completion, it needs to be emphasised that self-report enables people to express their own experience of pain and SCI, which is essential for patient-centred goal setting, allowing researchers to have a better insight into the perception of the dimensions of pain. For these reasons, research using self-completion measures should be encouraged.

11.5.5 SCIM III

Another limitation may arise from the psychometric properties of SCIM III. The subscale of "respiration and sphincter management" had the lowest internal consistency, particularly in the English version. This may be attributable to a number of factors. The translation into Greek may need improving as the translators found two of the four items in this specific subscale to be the most difficult to translate. But, the internal consistency for this subscale in the English version, which was not translated, was lower than the Greek version. This implies that the difficulty of the subscale was not because of the translation. It could be that the respondents may have had difficulty understanding the meaning of the questions and gave an approximate answer thus reflecting a potential difficulty with the wording of the subscale itself. This particular subscale had the lowest reliability in the original English version of SCIM III[222] which could indeed indicate difficulties with the wording of the subscale. Thus, some of the wording of SCIM III may need to be simplified without changing what the function intended to be measured.

Consideration also needs to be given to the type of the injury of the participants which may have affected the results of SCIM III which was originally tested for use with pooled groups with both complete and incomplete injuries.[64,222] When a measure is used under different conditions from that originally intended, its characteristics may be different.[96] Future researchers need to examine SCIM III in incomplete SCI only to investigate this concern. If similar findings emerge, then adaptations to the SCIM III may be required in order to take account the completeness of the injury of the respondent.

The high level of ceiling and floor effects, which were beyond the recommendations for a good health measure,[295] need to be reflected upon. There have been other studies in the literature to report similarly high ceiling effects of measurements[295] including the SF-36[1] and the SCIM III[3] or SCIM II,[495] which may flag up concerns about the suitability of a tool for usage with certain patient groups. The high percentage of ceiling effects found here could be attributed to the fact that the respondents were less impaired as they all had incomplete SCI. Ackerman et al[3] used SCIM III to study people with complete SCI and found a higher percentage of ceiling effects among people with less impairment, which is in line with the findings of the current study. Both the studies of Ackerman et al[3] and Wirth et al[495] found SCIM to respond to change. They included people with complete injury and within the first year of their injury. This means that overall function may have been at lower levels, thus improvements in function could be picked up easily by the SCIM. But, the ability of SCIM III to discriminate progress in function for a group of people with incomplete injury and after a long time since injury may be limited, as people may have adapted to their new functional needs and limitations thus scoring higher on SCIM at baseline. However, as time since injury progresses and the person with SCI is ageing, SCIM III maybe more capable of discerning a reduction of function in incomplete SCI. Direct comparisons for response to change cannot be made with the two above-mentioned studies and the author can only speculate on these assumptions because SCIM III was not used to asses functional changes in a before-and-after study design. The author recommends future investigation for SCIM III to examine the above mentioned concerns.

11.5.6 Pain onset

This study asked respondents to state the onset of their pain categories following injury and there is no reason to believe that the respondents did not refer to pain acquired *after* their injury. However, the pain experience prior to injury and how this may have affected the experience of pain following injury was not examined. In short, whether there were any pain risk factors prior to iSCI was not investigated. It may be important that future

studies include some questions which examine predisposing or precipitating factors for the onset of pain post injury.

11.5.7 Technical difficulties

The final limitation arose from technical problems during the data collection. The way the body chart was presented to the respondents may have created difficulties in completing it, thus not capturing the extent of pain efficiently. The second technical problem related to the difficulty, at the time, of designing a VAS for online usage as was originally intended when the questionnaire was designed, resulting in using the NRS instead. To resolve this problem, responses given using the VAS were excluded due to differences found in the results. As most of these responses came from the Greek group, comparisons with this country when referring to intensity of LBP are of limited value. It is therefore recommended that studies use the same scale (i.e. NRS or VAS) to collect data.

11.6 Suggestions for future studies

While this study has successfully filled in some of the gaps identified during the literature search and has achieved its purpose of describing the experience of LBP in iSCI, it has also detected a number of areas for further research, many of which have already being addressed. They are presented together below.

11.6.1 Regression analysis

The first area for further research is to expand on the current analysis conducted and identify predictors either in a future secondary analysis of the current data or as an independent study. Multifactorial models could be designed using stepwise (backward)

multiple regression analysis to identify predictors for 1) LBP presence, 2) reduction in QoL, and 3) reduction in function in iSCI.

For the first model, it is suggested that logistic regression analysis could be used to predict LBP presence and could include the following factors:

1. Level of injury	2. Age
3. Cause of injury	4. Gender
5. Presence of MSKP	6. Number of areas with pain
7. Country of residency	8. Anxiety/depression

For the second model, it is suggested that multiple regression analysis could be used to predict QoL and could include the following factors:

1. Employment	2. Age
3. Cause of injury	4. Level of injury
5. Presence of pain in general	6. Presence of MSKP
7. Presence of LBP	8. Number of areas with pain
9. Number of pain days felt per month	10. Country of residency
11. Pain onset post injury	12. LBP onset post injury
13. Quality of LBP	14. Intensity of LBP
15. Anxiety/depression	

Finally, for the last model, it is suggested that multiple regression analysis could be used to predict function and could include the following factors:

1. Age	2. Level of injury
3. Presence of pain in general	4. Presence of MSKP
5. Presence of LBP	6. Pain onset post injury
7. Quality of LBP	8. Intensity of LBP

In a regression model used to predict outcome the variables to be included should be found significant in bivariate analysis[351] which was the case with most of the variables proposed in the above three models. However, in cases where some variables are not significant in bivariate analysis, but past experience indicates that they are important, they could also be included in the model.[351] Such variables have been proposed for inclusion in the above models, for example, gender and age as predictors of LBP or the various pain categories and age as predictors of function. Future researchers may want to include other psychosocial variables which may predict LBP presence or changes in QoL and function.

11.6.2 Further validation of GR-SCIM III and SCIM III

As already mentioned, the psychometric properties of SCIM III and GR-SCIM III should be further explored in future studies. These studies should include people with both complete and incomplete SCI. They could compare usage of the measure by self-completion and observation and use a before-and-after design to enable examination of sensitivity to change. Further attention will need to be given to the subscale of "respiration and sphincter management" for both the SCIM III and GR-SCIM III as they were found here to have low internal validity. The wording of the subscale may require simplification.

11.6.3 Further cultural analysis

Although this study looked at differences and similarities in the variables of interest between and within the groups from the three participating countries, it cannot claim that it directly looked into cultural impact. The three countries have similar development profiles, which may be affected by social structures and health systems, but probably have different cultural and possibly religious structures. Global migration is more extensive in

the USA and UK compared to Greece. In addition, Greeks tend to register under one single religion and, among the three countries, it is probably the country with the most unified culture. A future study may look into cultural influences including variables like religion, race/ethnicity, cultural expectations and their impact on the categories of pain, QoL and function in iSCI. There is also a need to examine the impact of health care systems on the experience of living with iSCI and pain, particularly in Greece. An in-depth interview study design would provide essential information.

11.6.4 MSKP, gender and assessment scales

A future study could seek to examine in more detail the differences of the impact of MSKP on QoL and function between genders. Assessment scales or the ISCIDS may consider adding some items about the perception of QoL between genders when MSKP is investigated. A pain measure adapted differently for men and women, particularly to examine MSKP, could be a proposition.

11.6.5 Standardised measures for web-surveys

As pointed out beforehand, internet research is an area with great potential. The use of technological advances to survey people will benefit research as it will strengthen results by enabling large-scale studies to be conducted more easily. The SF-MPQ, and other self-completed measures, could be designed for online completion by people with physical disabilities. It is known from Dworkin et al[129] that the new version of SF-MPQ (SF-MPQ-2) was used online for initial validation testing. The use of SF-MPQ online will be a very valuable tool for research in the field of pain.

2-D body charts have been used for years in clinical settings or in postal surveys and advancing technology has transferred the body chart or pain questionnaires into hand-held devices.[82,355,385] More recently, pain drawings have been made into 3-D forms in PDAs

and have been used to assess pain in studies including people with SCI or back pain[167,416] with very promising results in the study of pain. The online format of the body chart used in the current study presented some technical difficulties thus updating the body chart for such use would be a useful tool in future pain research.

11.6.6 Post-thesis secondary analysis

A post-thesis secondary analysis, or an analysis of data not currently presented as they were not part of the objectives of this project, could also be undertaken. This analysis could include; 1) more detailed examination of the body chart focusing on areas other than the back, 2) analysis of the data from respondents who had a complete injury (and were excluded from the current analysis), 3) analysis of the available data from people who dropped out and 4) treatment, accessibility to treatment and social support available to respondents. This post-thesis analysis may identify further significant or important variables that could be included in the three prediction multifactorial models proposed above.

Finally, a future study could build on and adapt the purpose of an intervention study originally designed, but not conducted (see postscript), prior to this study which planned to use a 3-dimensional movement therapy to treat pain.

11.6.7 Repeating the study

The design and methodology of this study could be repeated in a new project which could use the following comparison groups; 1) people with complete SCI, and 2) people with LBP from the general population. The aim would be to enable direct comparisons between these groups in order to seek to answer, with more precision, questions about “if” and “how” these groups differ and “if” and “how” these differences affect the experience of pain.

11.7 Reflection upon personal experience

Planning, conducting and writing up this study has been a journey full of challenges, as well as the acquisition of new knowledge and skills. Throughout the PhD journey, reflection has helped to identify both strengths and weaknesses related to the project but also to me personally. These learning skills can now be transferred to my future research environment.

The current project was developed following a critical moment in my PhD studies, which necessitated taking a crucial decision to make a radical change in the direction of the PhD and terminate a randomised controlled trial (RCT) and to design the current study instead. RCTs are considered to be the "gold standard" in research methodology[203] and, at the time, it felt difficult to accept a changed methodology and study design. However, combining knowledge gained from the original project, together with guidance from the literature and a personal desire to design a survey which would use techniques that would make it a "good" survey, the current project emerged. As the project developed, it became more interesting and more stimulating. With the phrase of Winston Churchill in mind "*There is nothing wrong with change, if it is in the right direction*",[399] this particular learning experience is one of the most valuable I take with me from this PhD.

On being given the opportunity to create a study that could involve more than one country, the desire to include my native country and the wish to contribute to the knowledge in the field of SCI in Greece was great. This personal desire was also an important field of research as such studies in Greece are scarce. In addition, the assessment tool translated into Greek could then be used by Greek therapists in clinical practice or by researchers in future projects.

During the period of conducting the study further challenges emerged. Running the study in three different countries was one of the major challenges. This management was most challenging in Greece where data collection involved more than one method and there was a need to organise and set up appropriate links in order for the data collection to be

effective. Organising a team of people to work on the translations of the Greek version of the questionnaire was another challenge, but I was fortunate enough to identify people who were willing to volunteer to assist in the study. Another challenge was to gain sufficient understanding of research methods, such that it became clear how and which methods were appropriate for this transnational study and then learn how to conduct the appropriate statistical analysis. Finally, and as life can never truly be put on hold in order to do a PhD, learning to manage some serious personal issues and their consequences at the same time was a valuable lifelong skill learned during this process.

As a physiotherapist, at the onset of my PhD, I had hoped to accomplish a thesis that would involve therapy for patients. The journey through this PhD taught me some of the challenges that may have to be faced while conducting research and the ability to take crucial decisions when necessary. But above all, it taught me that changes can be successfully accomplished if we develop the appropriate skills to manage them.

11.8 Summary of key messages and their contributions

This study influences the field of SCI by providing key messages that are anticipated to contribute to all the participating stakeholder groups; 1) researchers, 2) practitioners, 3) patients and 4) policy makers.

Researchers are expected to benefit on various aspects:

- First of all, the systematic literature review brings into attention the lack of research on CMSKP and more particularly on CBP and CLBP. This can become a point of reference for the researchers who are now encouraged to conduct further studies to confirm the findings of the high prevalence of LBP, and its greater interference with QoL and function (compared with pain in general) as shown in this research.

- This study showed that patients can self-report on their function with no particular problems. Undoubtedly, further testing needs to be conducted to confirm this and it is anticipated that researchers now will act upon this message. This study advises researchers to consider that SCIM III may need to be adapted when examining people with iSCI only.
- Another key finding expected to have a positive impact for people who work in the field of SCI in Greece is the availability of the first scale to assess functional independence. Greek researchers can now conduct studies to examine further the psychogenic properties of GR-SCIM III and compare it with other studies using the English, or other, versions.
- This research showed that the presence of pain or LBP does not negatively affect function in iSCI, on the contrary it may assist it slightly. However, worse intensity of LBP does affect function negatively. Researchers are encouraged to look into the reasons for increased motivation towards functional independence in iSCI despite the pain presence.
- This investigation confirms that gender needs to be separately examined when considering MSKP particularly in relation to QoL and function. Researchers of the ISCIDS can consider adding some items related with the perception of QoL between genders when MSKP is investigated.
- This study confirms that surveying people with a physical disability like SCI can be achieved. Researchers are highly encouraged to design more studies using the same techniques of data collection which will reduce the cost of the research, recruit larger samples and enable international studies all of which will facilitate the understanding of the experience of pain in SCI.

Practitioners are expected to benefit from this study in many ways too:

- This study raises awareness about the problem of LBP in SCI. Clinicians are urged to include regular and repeated assessment of this category of pain in their clinical practise. As the characteristics of LBP interfere with QoL and function it is essential

that clinicians work early on addressing these possible consequences of SCI and educate patients about them.

- Self-assessment of function will benefit clinicians as it will allow them to have an insight to the patient's perspective about their function. Practitioners will be able to better implement long term rehabilitation in the community in two ways: 1) using tele-rehabilitation to follow up and assess patients, 2) patients can assess themselves at various point times and feedback to their clinicians. As a consequence therapy outcome is likely to improve by the promoted clinician – patient therapy alliance.
- Clinicians in Greece can now use the GR-SCIM III to systematically collect, analyse, interpreter and compare their data, using a SCI related measure, which will help them to ensure that the most effective rehabilitation is followed.
- The confirmation that people with SCI can complete a survey online also benefits clinicians who can encourage their patients to use the internet and the computer to provide fast and regular feedback when living in the community. Usage of the computer can also promote QoL.

Patients are expected to benefit in several ways from the findings of this study:

- Awareness about the problem of LBP is promoted for patients, who work alongside clinicians on the "expert patient" model of rehabilitation.
- Self-assessment of function, which builds on calls to examine function by the patients' perspective (Dawson et al 2008), actively empowers patients in their rehabilitation plan which is essential in the "patient centred" model. Patients are expected to benefit cognitively by this empowerment as they can feel that their perception is taken into account and assessed by using a valid measure. Also, they can benefit physically as by regular self-assessment they can monitor changes in their function and act appropriately in manner time.
- The message of this study on the applicability of the internet to survey people with iSCI has a positive implication to the patients themselves. More people can be

identified from around the world who have their "say" and include them in the process of making general decisions about care and future directions in SCI.

11.9 Conclusion

In conclusion, the main research question of the project "Do people with iSCI have LBP and what is their present and usual pain experience?" was answered by examining the experience of pain including examination of the extent, intensity and quality of pain focusing on the area of LBP. In addition, the effect of pain, concentrating more on LBP, QoL and function were investigated as further goals of the study.

This study demonstrated that people with iSCI have a high chance of suffering from LBP which may be of musculoskeletal origin. Usually LBP appears in the first six months following injury, is of moderate intensity and remains stable over time. It is described as "aching" and "tiring-exhausting" and is perceived as a "discomforting" experience. The presence and the worsening of the quality and intensity of LBP are related to a worse QoL. The presence of LBP does not relate significantly to function but increased intensity of LBP relates to worse "indoors and outdoors" function.

Among the three participating countries some differences in the results were noted though, overall, these were not major. The Greeks differed from the other two groups in both the cause of injury and the age of the participants which may have affected the results found. Greeks reported significantly less pain in general but not LBP. Their LBP was less constant and of slightly better quality. The group had more cases of "anxiety/depression" and Greeks perceived their health status as worse compared to people from the other countries. Finally, they reported the best functional independence compared to the other participants. But if pain or LBP was persistent, this had a more negative effect on their function compared to respondents from the other countries. Hence, overall, Greeks reported a less severe experience of pain, they functioned better than others but believed that their health status was worse. As pain reports can be

affected by culture or personality,[76] this area needs to be further explored. Beliefs about pain, such as catastrophising, may have a worse impact on QoL than pain intensity;[257] thus, it may be that such aspects of the LBP experience in the Greek group may lack the necessary attention. In Greece, back pain clinics or SCI units are minimal especially in provincial areas. Greeks may lack the appropriate understanding provided by their health carers of how to deal with the cognitive aspect of pain. If these are concerns in the Greek population with iSCI then the Greek health professionals need to pay more attention to such perceptions and include therapy options, like CBT to assist in dealing with them.

The UK group differed from the other two groups in that they reported the highest (but not statistically significant) prevalence of all the pain categories examined. They reported the worst (but not statistically significant) quality and intensity of LBP. They used the most descriptors to describe their LBP and more people, compared to the other countries, perceived it as “discomforting”. They reported the worst (but not significantly different) health index and significantly worse total function. When the quality of LBP became worse, it had a more negative correlation with QoL than occurred when the same happened to respondents from the other countries. The presence of pain related to stronger, negative correlations with functional reduction compared to the other two groups. Consequently, people from the UK were more severely affected by the experience of pain, which then correlated with their health status classification and their function.

The USA group was the biggest group and often statistically significant results found for the pooled group maintained their significance only within the USA group in the cross-national analysis. The fact that this group was larger in size may have contributed to this. Respondents from the USA were the youngest among the participants and their LBP was of moderate severity. Their overall pain experience was not as severe as that of people from the UK. Similarly, as already mentioned, their QoL was slightly better and their function was significantly better than for people from the UK.

The findings of this study provide new information and propose directions for research, clinical assessment and rehabilitation. The study brings to the surface a topic given little attention in the literature, as shown by the systematic review, but one of significance to the patient, as found in the survey conducted. It shows that the presence of pain can be disabling but there may be other factors, not examined here, possibly psychosocial, that may motivate people with iSCI to overcome it and remain active. The findings conclude that self-assessment of function in iSCI can be reliable which will help in the long-term rehabilitation goals of the patients. Empowering patients and motivating them to become active participants in their own rehabilitation plans, offering them self-assessment tools to do so, will undoubtedly have a positive impact on them, their families and carers. Early management of pain and LBP could lead to a reduction in recurrence of pain, chronicity of pain, hospital visits, keep health costs down and, above all, increase the QoL of the patient.

Postscript

Picture copyrighted to

George (Giorgos) Michailidis, 1969 -

“There is nothing wrong with change, if it is in the right direction”

Winston Churchill, (1874 – 1965) - British politician and Prime Minister

1. Original study plan

The original plan of this thesis was to conduct a single-blind, experimental, randomised controlled trial using two types of participants: people with iSCI and children with cerebral palsy (CP). The aim was to investigate the therapeutic effect of 3-dimensional movement, via using the Brunel Active Balance Saddle (BABS) which is a horse simulator, on pain (including LBP), balance and posture.

2. Study methodology

Preliminary information was collected for the study by developing two questionnaires and sending them to two different samples; 1) physiotherapists working in the National Health Service (NHS) with people with neurological conditions including SCI and 2) therapists providing horse riding treatment. The aim was to ask the therapists directly about pain (including LBP), balance and posture problems among their patients, reasons for developing these problems and to identify therapies used to treat them, including horse riding.

The NHS sample was selected using simple random sampling technique via information available on the NHS website. Thirty-nine physiotherapy units entered the final sampling frame. As this survey was done for exploratory reasons, 25 participants were believed to be sufficient to provide the information needed to design the next stage of the project. Twenty-six questionnaires were returned.

To identify eligible participants for the second sample, the Association of Chartered Physiotherapists in Therapeutic Riding (ACPTR) members' list was used and questionnaires mailed to randomly selected people from the list. Twenty-seven questionnaires were collected.

The second stage of the study involved the main trial. Using information gathered from the questionnaires and by reviewing the literature, the study was designed. The

assessment tools to be used were selected, volunteer physiotherapists to participate in the study had been identified and a lab at the School of Health Sciences and Social care hosted BABS and was ready to host the trial.

3. Ethical approval and research and development (R&D) approvals

The proposal for the study was submitted to a Multicentre Research Ethics Committee (MREC). Following corrections and amendments ethical approval to conduct the trial was granted nearly one year post original submission of the proposal to the Ethics Committee. The next step involved gaining research and development (R&D) approvals via Primary Care Trusts (PCT) and hospitals. More than one year after the MREC ethical approval, only two R&D approvals were given, five were pending and others had declined. Twenty-five eligible participants (people who expressed interest in the study) were identified but access to their medical records was not yet granted. The time-consuming procedures to obtain approvals led to insufficient recruitment in the time frame available and, as a result, the study was terminated.

4. Moving on

Not completing the PhD was not an option for me. Following reflection upon the information gathered thus far, a different approach and a new project was designed. The vast majority of the physiotherapists, who returned the questionnaire sent to them as part of the original project, and who worked in the NHS, said that up to half of their patients with neurological disabilities had LBP. They also said that their patients would only complain about their pain when it interfered with everyday activities, when pain was acute and when asked. It was interesting to note that more than one-fifth of the therapists said that their patients would report their pain only when asked. This implies that pain is present but not necessarily recorded. This was one of the main reasons that led to the development of the current project of this thesis, which has been described in Chapters 1-11, and which directly asked people to report on their pain.

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Appendix 1; Systematic literature review

Supplement to Chapter 3

Table 1: Criteria for allocating studies to research questions

Article	Source of sample	Chronic Pain definition started (≥3 months)	Chronic pain definition provided by author	Tool assessing chronic pain (≥3 months)	Report on musculoskeletal pain	Report on back pain	Report on LBP
Rintala et.al[381]	community	lasted or recurred over at least 6 months	_____	None used	Yes	Yes	Yes
Barrett et.al[19]	secondary	NR	_____	CPGQ	Yes	No	No
Cardenas et.al[58]	community	NR	_____	CPGQ	Yes	No	No
Siddall et.al[406]	community	NR	_____	CPGQ	Yes	No	No
Cruz-Almeida et.al[90]	community	NR	≥3 months	None used	No	Yes	No
Rintala et.al[382]	community	continuous or intermittent for at least 6 months	_____	None used	No	Yes	No
Ullrich et.al[457]	community	NR	_____	CPGQ	No	Yes	Yes
Raissi et al[371]	community centres	NR	_____	Not known	No	No	Yes

Abbreviations: NR, Not Reported; CPGQ, Chronic Pain Grade Questionnaire; LBP, Low Back Pain

Table 2: Description of the selected papers under review

Paper or paper groups selected	Description	Design
Rintala & co-authors		Longitudinal over 10 years involving a 13-county area in the USA – multiple publications
Rintala et al[551]	Reports from all 2 points (phases) measurements. Includes both males & females. Larges sample than 1998 study. Describes only people participating in all 4 stages. No report on MSKP. Physical examination done at phase 1.	
Rintala et al[550]	Reports only on males. Reports on MSKP. Response rate 85.5%.	
Overall comment	Some of the variables measured differed at the different phases (e.g. social support was only measured at points 1 and 2). Each phase (duration of study) lasted two years followed by a one year gap. The author provided us with additional information about the number of participants with complete/incomplete paraplegia/tetraplegia, and the exact number of people reporting pain at each area of the body. Data from both publications will be used to address our research questions.	
Barrett et al[19]	People admitted to hospital for complications following their SCI. The participation rate 80%. Pain time frame not reported but the Chronic Pain Grade Questionnaire (CPGQ), which is a standardised measure to assess chronic pain, for at least 3 months, was used. Physical examination of the patients assumed.	Cohort interview
Cardenas et al[35]	Random selection of participants who were registered with a SCI mailing list. Aim to determine inter-rater reliability of a classification system proposed for chronic pain in SCI. Return rate 60% and only people with pain were described. The CPGQ was used.	Postal survey
Siddall et al[406]	Looking at pain characteristics 5 years post injury and admission to a Spinal Injuries Unit. Aim to find associations between pain and physical or psychological factors. The author confirmed that the sample had been based in the community at the time of recruitment. A pain time frame was not reported however the CPGQ was used. Response rate to the study was 73%. Location, description and apparent origin of pain conducted via telephone interview.	Longitudinal telephone interview
Series of publications	Originally participants identified via the Miami Project Databases.	Series of publications Postal surveys
Widerstrom-Noga et al[452]	First paper. Aim to find perceived difficulties in dealing with the consequences of SCI. Return rate 49%.	
Widerstrom-Noga et al[453]	Second study sent to 330 people living in the community who previously reported having pain. Aim to define relationships among clinical characteristics of pain after SCI.	
Widerstrom-Noga[454]	Another publication of the second study. Aim to investigate characteristics of non-painful sensations and compare them to chronic pain in SCI. Return rate 66%.	
Widerström-Noga and Turk[457]	Surveyed 258 people of the first study sample who complained of pain. Aim to gather information about factors associated with pain therapies.	
Cruz-Almeida et al[20]	18-months follow up study of the Widerstrom-Noga et al[33] study. Aim to determine stability of pain patterns and characteristics. Return rate 87%. Authors provided us with additional information related to cause of injury and percentage of back pain.	
Overall comment	These 5 publications will be treated as one study and results analysed as appropriate. No particular reference to MSKP. 3 papers referred to back pain.	

Table 2 continued: Description of the selected papers under review

Paper or paper groups selected	Description	Design
Rintala et al[380]	Aim to find prevalence and characteristics of chronic pain in SCI/dysaesthesia in a group of veterans recruited via a SCI veterans' centre. Response rate 66% and some additional information about the number of participants with complete/incomplete paraplegia/tetraplegia, and the exact number of people reporting pain at each area of the body was provided to us.	Cross-sectional telephone interview
Multiple studies		Postal survey
Turner et al[451]	University led study. Aim to study pain in SCI. Return rate 64%. CPGQ was used.	
Jensen et al[36]	Surveyed people who had participated in two previous studies, one of which was Turner et al. (Turner et al., 2001) Aim to assess severity of pain in SCI and change of pain prevalence and intensity at specific sites. The results were compared to national norms. Return rate 49%.	
Overall comment 1	Further publications were identified[38, 39, 40, 44] and differences in the reported sample size for each paper were noted. Following personal communication with the authors it was explained that the publications were products of the longitudinal study by Jensen et al (2005)[36] but surveys were mailed out in waves therefore resulting in additional participants. It was also confirmed that the participants largely came from the study by Turner et al (2001)[43] and also that each sub-study included subjects from the previous (Jensen et al., 2005) [36]but only reported on people who had provided complete data for the variables investigated in the particular study.	
Raichle et al[370]	Examined the biopsychosocial model in order to understand and treat pain in SCI. Return rate 50%.	
Molton et al[318]	Another publication from same study related to "Motivational model of pain self-management".	
Ullrich et al[457]	Used data only from people who had reported current pain aiming to check the characteristics of pain location, intensity and interference and also to examine the areas of the body with more intense pain.	
Hanley et al[190]	Is a six months follow-up study of Jensen et al. (2005).[36] Due to an administrative error, the whole sample was not surveyed. Aim to examine how coping, cognitive and social environment associate with psychological functioning and pain interference at six months follow-up.	
Overall comment 2	Even though the subjects of each of the sub-studies did not overlap 100% of the time, the subjects mainly came from the same group, therefore it was decided to group all these publications as one study, starting from Turner et al. (2001).[43] None of the papers made particular reference to MSKP in general but they referred to BP or LBP.	
Raissi et al[371]	Studied people who sustained a SCI following an earthquake in Iran aiming to investigate pain among other things. They worked on the earthquake site immediately after the event (for three months) and they returned for evaluations at eight months. Physical examination was conducted. They report on LBP.	Physical examination at patients location (residence or treatment centres)

Table 3: Description of participants as reported in the studies

Article key Number	N of participants Males/Females	Cause of Injury	Level/Completeness of Injury N of participants	Time since Injury (years) mean±SD, min-max	Age of participants mean±SD, min-max
Rintala et al[381]	n=77 77/0	36 motor accident 14 sport, 14 violence 6 fall, 7 other	34 tetraplegia, 30 paraplegia 67 complete (motor) 10 incomplete (motor) 10 missing level	13.25±8.64 3-51 years	40.99±12.32 (study) (range 22-80)
Barrett et al[19]	n=88 75/13	28 motor accidents 17 fall, 21 diving/water sport 3 horse, 19 other	53 tetraplegia, 35 paraplegia	16.68±12.6	48.4±13 (study)
Cardenas et al[38]	n=163[1] 114/49	80 motor accidents 32 falls, 51 missing	85 tetraplegia, 76 paraplegia 2 unknown level Completeness NR	8.3±8.9 5-33	17-77 (study)
Siddall et al[406]	n=73 60/13	Traumatic[2]	36 Tetraplegia, 37 paraplegia 28 complete, 45 incomplete	5.2-5.6	Mean 40 (study) (range 21-81)
Cruz-Almeida et al[90] (group study)[3]	n=430 329/101	208 motor accident 50 falls, 53 diving 42 gunshot, 26 sport injuries 51 other	241 tetraplegia, 187 paraplegia 160 complete 248 incomplete	8.1±5.4	29.4 (at injury) 37.5 (±11.8) (at study)
Rintala et al[380]	n=348 345/3	130 motor accident 59 falls, 30 diving 21 gunshot, 19 sport 76 other	112 tetraplegia, 133 paraplegia 103 not reported	17±12 0.3-60	37.3±13.8 (injury) 54.8±11.6 (study)
Ullrich et al[457] (group study)[4]	n=384 283/101	179 motor accident 59 falls, 30 diving 21 gunshot, 19 sport 76 other	59 C1-4, 138 C5-8 tetraplegia 42 T1-5, 111 T6-12 paraplegia 34 L1-S4/5 paraplegia 143 complete, 185 incomplete 54 not known	12±9.67	42.5±13.8 (study)
Raissi et al[371]	n=54 25/29	54 earthquake	3 tetraplegia, 51 paraplegia 4 incomplete but for rest unclear	8 months	31.9±9.6 (study)

[1] Only the demographic characteristics of the 163 (out of the 215) patients (who reported pain) were described, [2]No information given to the specific causes of the traumatic injury, [3]Demographic and SCI characteristics are from Widerström-Noga (1999),[492]; [4]Demographic and SCI characteristics are from Turner et al.[451]

Table 3 continued: Description of participants as calculated in the super-sample

Super-sample	**N of participants Gender Ratio** (M:F)	**Cause of Injury**	**Level/Completeness of Injury** N of participants	**Time since Injury (years)** mean±SD, min-max	**Age of participants** mean±SD, min-max

Studies discussing CMSKP	n=453	n=277;
		144 (52%) motor accident,
		55 (20%) fall,
		22 (8%) diving/water accident,
		14 (5%) gunshot,
		17 (6%) sport accident,
		25 (9%) other
			n=399;
			211 (53%) tetraplegia
			188 (47%) paraplegia
			n=73;
			28 (38%) complete
			45 (62%) incomplete
				Range 3 – 51 years	Range 40 – 48 years

Studies discussing CBP or CLBP	n=1312;
	M=823 (63%)
	F=489 (37%)
		n=1311;
		558 (42.6%) motor accident,
		166 (12.6%) fall,
		238 (18%),
		82 (6.3%) diving/water accident,
		80 (6.1%) gunshot,
		78 (6%) sport accident,
		62 (4.7%) violence,
		53 (4%) earthquake
			n=1302;
			654 (50.2%) tetraplegia,
			648 (49.8%) paraplegia
			n=1154;
			473 (41%) complete,
			681 (59%) incomplete
				Range 8 months – 17 years	Range 29 – 55 years

Table 4: Percentage of chronic pain per body areas

Article key Number	Trunk	Back	Upper Back	Lower back	Buttocks
Rintala et al[381]	1% (a.a.p) 1.4% (a.p.p) (n=8)	34.4% (a.a.p) 47.1% (a.p.p) (n=13)	NR	NR	NR
Cruz-Almeida et al[90]	NR	60% (a.p.p) (n=130)	NR	NR	52.8% (a.p.p) (n=115)
Rintala et al[380]	14.1% (a.a.p) 16.1% (a.p.p) (n=49)	13.5% (a.a.p) 17.7% (a.p.p) (n=47)	NR	NR	NR
Ullrich et al[457]	NR	46.3% (a.a.p) 58.6% (a.p.p) (n=178)	29.6% (a.a.p) 40.8% (a.p.p) (n=97)	42.7% (a.a.p) 58.8% (a.p.p) (n=140)	32.9% (a.a.p) 45.4% (a.p.p) (n=127)
Raissi et al[371]	NR	NR	NR	29.6% (a.a.p) 30.7% (a.p.p) (n=54)	NR

[1]Under the group publications referenced as[90] are the characteristics as presented in Widerström-Noga 2003[484]
Abbreviations: a.a.p, Among all participants; a.p.p, Among participants with pain; NR, Not Reported.

Table 5: Description of chronic pain participants as described in the studies

Article key Number	Pain prevalence (%)	Pain Classification	Type of pain classification (%)	Total number of areas of pain per person	Pain question is about
Rintala et al[381]	75 (n=58)	Musculoskeletal Segment Central Visceral Psychogenic	42.9 (n=33) 31.6 (n=25 components) 10.1 (n=8 components) 7.6 (n=6 components) 0	*1.29*	Pain intensity for the day of exam Maximum & minimal intensity Average intensity for previous week
Barrett et al[19]	75 (n=66)	Musculoskeletal Visceral At-level neuropathic Below-level neuropathic Allodynia	43.6 (n=26) 15 (n=10) 11.4 (n=8) 24.35 (n=16) 5.7 (n=4)	35% (n=23) 1 area 65% (n=43) 2 areas 33% (n=22) 3 areas 10% (n=6) 4 areas 4.5% (n=5) 5 areas	Average intensity & severity rated over the week
Cardenas et al[56]	75.8 (n=163/215)	Neuropathic (includes SCI pain, transition zone & radicular) Musculoskeletal (including mechanical spine and overuse) Visceral Unable to categorise	*37.7 (n=81)* *28.4 (n=61)* 2.3 (n=5) 7.4 (n=16)	NR	Current pain problem
Siddall et al[406]	81 (n=59)	(Siddall et all 1997)[57] Musculoskeletal Visceral At-level neuropathic Below-level neuropathic	 59 (n=43) 5.4 (n=4) 41 (n=30) 34.2 (n=25)	*1.9*	NR
Cruz-Almeida et al[90]	76.6 (n=330)[1]	(Widerström-Noga et al[76]) Neuropathic pain below-level Upper limb pain in tetraplegia Severe, persistent pain	3.7±1.7 65 (burning) 61 (aching) 53 (sharp)		Presence of pain during past 3 months Pain intensity for current, most intense and least intense pain
Rintala et al[380]	81 (n=283)	Above level Above & at level Above, at & below level At level only Below level At- & below-level Unable to categorise	7 (n=25) 5 (n=17) 5 (n=17) 11 (n=38) 37 (n=129) 29 (n=101) 6 (n=21)	1.04	Average intensity for past week, intensity of worst pain
Ullrich et al[457]	79.2 (n=304/384)[2]	Above level At level Below level	41 (n=114/294)[2] 50 (n=138/294)[2] 83.2 (n=245/294)[2]	3.3 (972 pain sites)[2]	Presence of current pain Average intensity of past week
Raissi et al[371]	96.3% (n=52)	None reported	None reported	96.3% (n=52) 2 areas 5.5% (n=3) 3 areas	Presence & intensity of current pain

Results in italics are after this review's calculations, NR: not reported, [1]Under the group study referenced as Cruz-Almeida et al., 2005[90] characteristics of participants taken from study Widerstrom-Noga et al., 2001,[488]; [2]Information taken from Turner et al.[451]

Table 6: Characteristics of CMSKP, CBP and CLBP

Article key Number	Assessment tool used	Onset of pain	Pain severity or description	Pain intensity mean±SD	Pain related disability
Rintala et al[381]	SF-MPQ[1] NRS[2] Body diagram	NR	NR	3.5	
Barrett et al[19]	NRS VRS[3] CPGQ	18.02±11.4 years	77% mild/moderate 23% severe/excruciating	57.4±26.7	Reported for all pain
Cardenas et al[58]	SF-MPQ VAS[4] CPGQ	NR	Mechanical spine pain 93.5% aching 76.1% tiring-exhausting 69.6% sharp, 58.7% tender 56.5% stabbing, 54.3% shooting 52.2% throbbing 76.1% nagging¥, 71.7% tight¥	Mechanical spine pain 18.02±11.4 years[§] 53.7 (±21.2) Overuse pain 53.6 (±19)[§] 54.8 (±19.8)^^	32.8% Grade I 21.3% Grade II 19.75 Grade III 26.2% Grade IV
Cruz-Almeida et al[90]		58.5% <6 months (n=72) 36.6%>6 months (n=45) 35% <1 year (at level) 28% 1-10 years (below level) 37%>10 years (at & below level)			
Raissi et al[371]	NRS	87.5% of those with LBP started after injury		46.3% scored 10 (0-10 scale) 64.8% scored >5 (0-10 scale)	

[1]SF-McGill Pain Questionnaire, [2]1-5 scale,[3]Verbal Rating Scale; using mild, moderate, severe and excruciating, [4]VAS 0-100, [¥]Descriptor from original MPQ, [§]Mean for worst pain, ^^Mean for second worst pain, CPGQ; Reported for worst MSKP on the CPGQ; Grade I: "low pain intensity-low pain-related disability", Grade II: "high pain intensity and low pain-related disability", Grade III: "moderate pain-related disability" and Grade IV: "severe pain-related disability

Appendix 2; Questionnaire in English

Supplement to Chapters 4 and 5

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27 October 2008

Approval of Amendment to Protocol

Proposer: Christina Michailidou

Title: The study of pain experience and its effect on the lives of people with Spinal Cord Injury (SCI) in the United Kingdom (UK) Greece and the USA

Reference: 01/08/PHD/01

The School Research Ethics Committee has considered the amendment to protocol recently submitted by you in relation to the above study. Acting under delegated authority, the Chair is satisfied that there is no objection on ethical grounds to the amendment. Approval is given on the understanding that the conditions of approval set out below are followed:

- *The agreed protocol must be followed. Any changes to the protocol will require prior approval from the Committee.*

NB:

- Research participant information sheets and (where relevant) flyers, posters and consent forms, should include a clear statement that research ethics approval has been obtained from the School of Health Sciences and Social Care Research Ethics Committee.
- Approval to proceed with the study is granted subject to receipt by the Committee of satisfactory responses to any conditions that may appear above, in addition to any subsequent changes to the protocol.

David Anderson-Ford
School Research Ethics Officer
School of Health Sciences and Social Care

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4 September 2008

Approval of Amendment to Protocol

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David Anderson-Ford
School Research Ethics Officer
School of Health Sciences and Social Care

Participant information sheet for adults with Spinal Cord Injury

Dear Sir/Madam,

Study Title: "The study of pain experience, its intensity and its effect on the lives of people with Spinal Cord Injury (SCI) in United States of America (USA), the United Kingdom (UK) and Greece".

Invitation paragraph

You are invited to take part in a research study. Before you decide it is important that you understand why the research is being done and what it will involve. Please, read the information below carefully and discuss it with others if you wish.

- Part 1 tells you the purpose of this study and what will happen to you if you take part.
- Part 2 gives you more detailed information about the conduct of the study.

Ask me if there is anything that is not clear or if you would like further information. Take time to decide whether or not you wish to take part.

What is the aim of the study?

The aim of the study is to look into pain in general and Low Back Pain (LBP) in particular in people with Spinal Cord Injury (SCI). The experience of pain and how it may affect quality of life and function will be explored. Finally, different health service systems and cultural influences that may affect pain will be discussed as the study is taking place in the USA, the UK and Greece.

Why have I been identified?

You have been identified because you have SCI and you may fit the inclusion criteria of this study. A minimum of 185 people with SCI living in the USA, UK and Greece will participate.

How was I identified?

You accessed information about this study via the Spinal Injury Association (SIA). Due to the Data Protection Act I can not have direct access to your contact details. For this reason SIA was approached and asked to participate in this study. They have approved of this study and a local collaborator was identified and agreed to post this questionnaire on line or send it to you via email.

Do I have to take part?

No, it is up to you to decide whether or not to take part. If you decide to take part you have the option of replying anonymously. If you decide to give us your name we assure you that all personal information will be treated with strict confidentiality. A decision not to take part will not affect the standard of care you receive.

What kind of study is it?

This study is part of a larger PhD project that investigates pain in general and LBP in particular in adults with SCI and children with Cerebral Palsy. One of the aims of the complete PhD project is to investigate how a specific therapy based on 3-dimension movement could benefit LBP, posture, balance, function, and quality of life in these populations.

This current part of the project, in which you are invited to participate, consists of a self-completed questionnaire, which is included in this letter, aiming to be answered by people with SCI only. In the second part of this letter you will find detailed information on how to fill in the questionnaire booklet.

What are the possible benefits of taking part?

Pain has been found to be part of the everyday life of people with SCI and in many cases it may cause stress and anxiety and affect quality of life and interfere with every day activities. However, pain experience overall and LBP in particular have not been well studied in people with SCI.

It is expected that you will gain indirect benefits as the results of this survey will investigate questions related to pain and may contribute to raising awareness and provoking further studies aiming to improve pain symptoms, quality of life and function in people with SCI and pain.

What will happen to me if I take part?

All you will have to do is answer the enclosed questionnaire booklet and return it to me.

Will I have to pay anything?

No, you will not have to pay for anything. We provide you with a stamped addressed envelope for you to put in the completed questionnaire booklet and return it to me.

Are there any risks involved?

There are no potential risks expected as a result of your agreement to complete the questionnaire.

What if I do not have any LBP or any pain?

It is very important that you reply to this questionnaire even if you do not have any LBP or other pain. This will provide us with valuable information regarding the prevalence of pain and LBP in SCI and enable us to do statistical comparisons between the people who have and those who do not have LBP and pain. In the questionnaire booklet you will find instructions on which questions to answer if you do not have pain or LBP.

What if there is a problem?

No problem is expected, however if this is the case it will be fully discussed with you.

Will my taking part be kept confidential?

Yes. Any information about you that has your name and address is removed so that you cannot be recognised from it. All data will be kept in locked cabinets, located in the University building, and accessed only by me.

Thank you for reading so far – if you are still interested please, go to Part 2

Part 2

What will happen if I do not want to carry on with the survey?

If you decide to take part you are free to withdraw at any time and without giving a reason. A decision to withdraw will not affect the standard of care you receive. However, it will be impossible to withdraw questionnaires that have been returned anonymously as it will not be able to allocate a name to an anonymous questionnaire.

What if I want to complain about anything?

If you have a concern about any aspect of this study, you should ask to speak with the researchers who will do their best to answer your questions. You can contact me. If you remain unhappy and wish to complain formally, you can contact the supervisors of this study. Their telephone numbers are at the end of this information sheet.

Will my doctor be informed?

No, your doctor will not be informed about your decision to complete this questionnaire. However, if at any stage during the study it will be found necessary to inform your doctor then your consent will be asked in advance.

What will happen to the results of the study?

The results will be included in my PhD thesis within the next two years. Additionally, they will be published during the years after the PhD completion. If you wish, you could contact me and I can send you a report of the results or you can find them directly in the journals once published. Under no circumstances will your name be identified in any report or publication.

Who is organising and funding the research?

This study is sponsored by the School of Health Sciences and Social Care of Brunel University of West London and partially funded by the Engineering and Physical Sciences Research Council (EPSRC) and the Brunel University Graduate School. The supervisors of the study are Professor Lorraine DeSouza and Professor Ian Sutherland.

Who has reviewed the study?

Before any research can go ahead it has to be checked and approved by an Ethics Committee. They make sure that the research is ready to run. This study has been checked and approved by the School of Health Science and Social Care Research Ethics Committee. SIA has also reviewed the study and approved of the collaboration.

How long will it take me to complete the questionnaire and what does it consist of ?

It will take you approximately 1 hour to complete the questionnaire. We understand that this questionnaire may be long to complete but as it examines areas that have not previously been looked into such depth the data collected will be of great interest. You may wish to complete this questionnaire into stages.

The first part consists of three standardized questionnaires. They are the Short form McGill Pain Questionnaire, the EQ-5D and the Spinal Cord Independence measure.

The Short form McGill questionnaire examines pain and its dimensions. A body pain diagram where you can mark the area on your body with pain has been included. Pain intensity is measured on the Visual Analogue Scale (VAS). There is also a list of word descriptors that provide sensory, affective and evaluative information about your pain.

The EQ-5D questionnaire measures the quality of life and gives information about mobility, self-care, usual activities, pain/discomfort and anxiety/depression.

The SCIM provides information about function. It investigates the areas of self-care, respiration and sphincter management and indoors and outdoors mobility.

The second part of the questionnaire booklet consists of socio-demographic data aiming to collect information about your SCI history and treatment and to find how they may interact with the presence or not of pain and LBP. This part of the questionnaire may also help identify best treatment options.

I want to take part; What do I do now?

If you agree to take part but you wish to remain anonymous, please complete and return only the questionnaire booklet without writing your name anywhere in it. If you wish to give us your personal contact details, please, do so

when asked. The completed questionnaire booklet should be directly returned to me, the chief investigator of the study. If you are sending the questionnaire by postal mail please use the address provided below. If you are returning the questionnaire online it will automatically be returned to the chief investigator.

I want to take part but can not complete the questionnaire on my own

If you are having difficulties reading or completing this questionnaire on your own, please ask for the help of a member of your family or a friend. However, please make sure that you are answering the questions and they are helping you by writing them down in the paper questionnaire or ticking them on the electronic version questionnaire. When completing the VAS and the body pain drawing, please point to them as accurately as possible where your answer is.

If you need any further assistant, please do not hesitate to contact me.

Can I do it later?

Yes. We will be accepting returned questionnaires for at least one month.

I don't want to take part; What do I do now?

If you do not want to take part then please, ignore this letter. You may automatically receive a reminder letter in the near future. If you still do not wish to participate, then please ignore that reminder letter too. However, any information you provide us with will be most helpful.

Thank you very much for taking the time to read this information sheet. If you have any further questions please, feel free to contact me. If you wish to remain anonymous to me but require further information please contact SIA via email or telephone.

Additionally, if you need further information about your pain please refer to the SIA webpage. The link is: http://www.spinal.co.uk/b-04.aspx

Yours Sincerely,

Christina Michailidou, MSc, BSc in Physiotherapy

Study Chief Investigator

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Thank you very much for reading the information sheet

For office use:

Date Completed	
Date analysed	
Questionnaire PIN Number	
Centre Pin Number	
Participant Pin number	
Country	

We are very grateful for your help in completing these questions. The information provided helps us to understand more about spinal cord injury and the symptoms around it. Analysis of the results may help us develop future treatment options aiming to improve pain and quality of life for people with Spinal Cord Injury.

There are no **right** or **wrong** answers to these questions. We are most interested in your **own** personal views rather than those of your family or the people who are treating you.

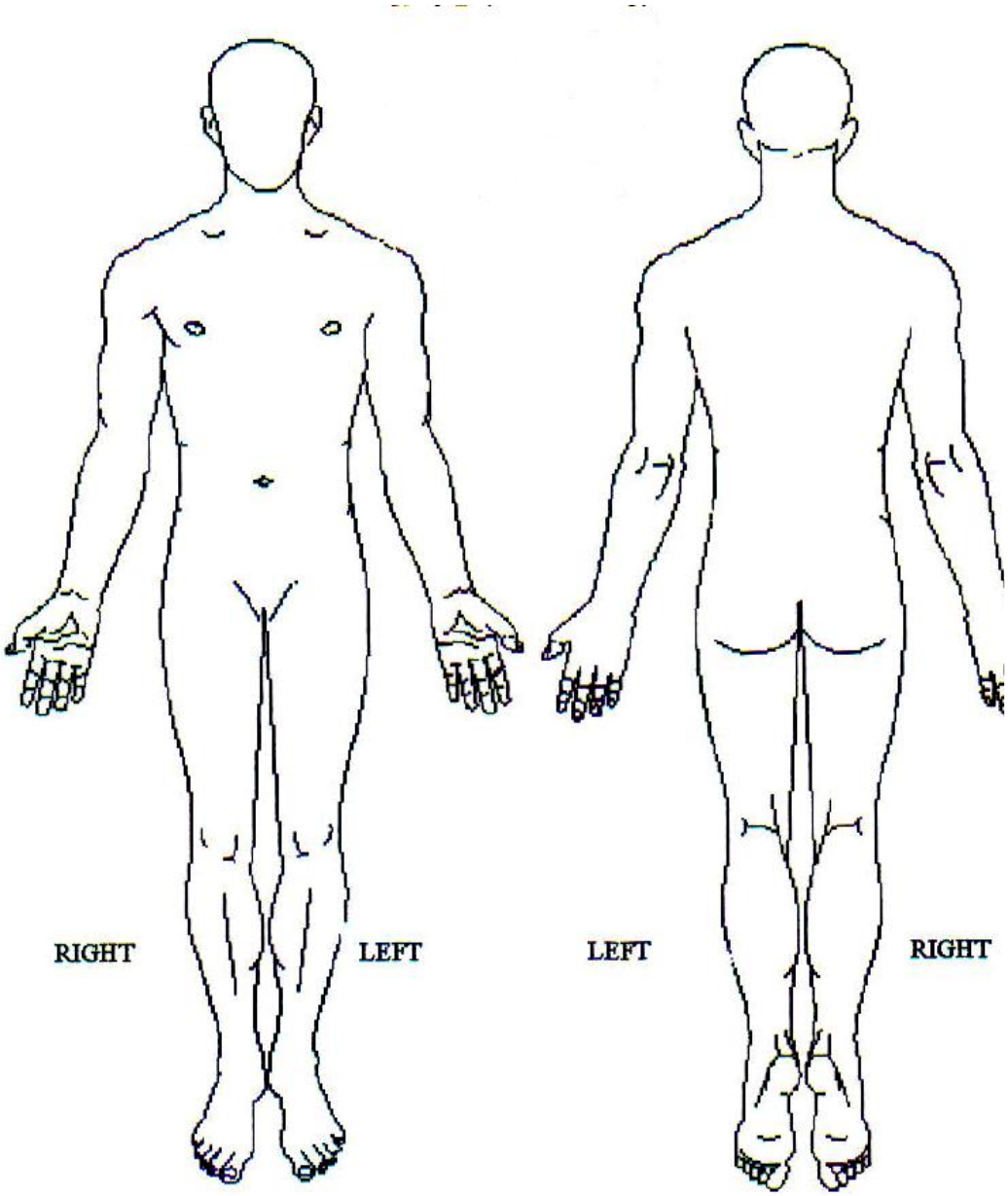
- **We would like you to answer the questions as honestly and as quickly as possible.**
- **If you find it hard to keep your mind on the statements, take a short break. The questionnaire may be completed over a day or two.**
- **Some questions are marked with an asterisk (*), at the beginning of them, which indicates that an answer is needed. Please, answer these questions if applicable to you.**
- **Based on your answers you may skip some questions. Please, follow the instructions of the questions as appropriate.**

Thank you very much

Abbreviations: Spinal Cord Injury (SCI), Low Back Pain (LBP), Visual analogue Scale (VAS), Pain Rating Scale (PRS), Present Pain Intensity (PPI), *answer the question if applicable to you

Short-Form McGill Pain Questionnaire

***This picture is a body drawing to help you indicate the areas where you feel pain.



Please, mark on the above drawing the areas where you feel pain. Put **E** if external, or **I** if internal, or **EI** if both external and internal pain is present near the areas you mark.

Abbreviations: Spinal Cord Injury (SCI), Low Back Pain (LBP), Visual analogue Scale (VAS), Pain Rating Scale (PRS), Present Pain Intensity (PPI), *answer the question if applicable to you

1) ***Since you got your SCI have you ever felt low back pain (**LBP**)?

Yes ❑ (please, continue with questions below)

No ❑ (please, go to EQ-5D, page 5)

I. **Pain Rating Index** (**PRI**).

The words below describe **average pain**. Place a check mark (√) in the column that represents the degree to which you feel that type of pain. Please, limit yourself to a description of the pain in your **lower back** (lumbar) area only.

	None	Mild	Moderate	Severe
Throbbing				
Shooting				
Stabbing				
Sharp				
Cramping				
Gnawing				
Hot-Burning				
Aching				
Heavy				
Tender				
Splitting				
Tiring-exhausting				
Sickening				
Fearful				
Punishing-Cruel				

II. ***Present Pain Intensity** (**PPI**) - Visual Analogue Scale (VAS).

Place a "**x**" mark along the line to indicate your **present** low back pain (**LBP**).

No pain |_____| **Worst pain imaginable**

➢ ***Usual Pain Intensity – last 3 months**.

Please, place a "**x**" mark along the line to indicate your **usual LBP** over the last **3** months

No pain |_____| **Worst pain imaginable**

Abbreviations: Spinal Cord Injury (SCI), Low Back Pain (LBP), Visual analogue Scale (VAS), Pain Rating Scale (PRS), Present Pain Intensity (PPI), *answer the question if applicable to you

- ***Usual Pain Intensity – last 1 month**.

  Please, place a "**x**" mark along the line to indicate your **usual LBP** over the last **1** month

No pain |_____| **Worst pain imaginable**

III. ***Evaluative overall intensity of total pain experience**.

Please, limit yourself to a description of the pain in your **lower back** (lumbar) area only. Place a check mark (√) in the appropriate column

Evaluative	
No Pain	
Mild	
Discomforting	
Distressing	
Horrible	
Excruciating	

EQ - 5D

Health Questionnaire

By placing a tick (✓) in one box in each group below, please indicate which statements best describe your own health state **today**.

Mobility

I have no problems in walking about ❑
I have some problems in walking about ❑
I am confined to bed ❑

Self-Care

I have no problems with self-care ❑
I have some problems washing or dressing myself ❑
I am unable to wash or dress myself ❑

Usual Activities (*e.g. work, study, housework, family or leisure activities)*

I have no problems with performing my usual activities ❑
I have some problems with performing my usual activities ❑
I am unable to perform my usual activities ❑

Pain/Discomfort

I have no pain or discomfort ❑
I have moderate pain or discomfort ❑
I have extreme pain or discomfort ❑

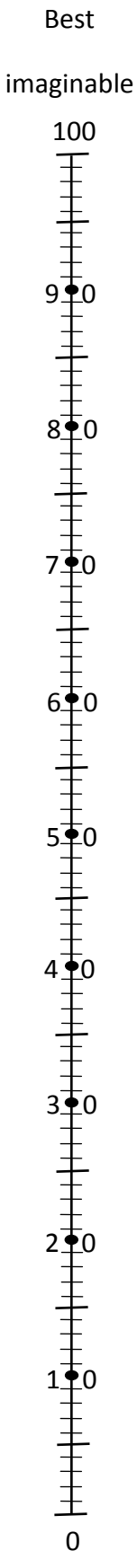
Anxiety/Depression

I am not anxious or depressed ❑
I am moderately anxious or depressed ❑
I am extremely anxious or depressed ❑

*To help people say how good or bad a health state is, we have drawn a scale (rather like a thermometer) on which the best state you can imagine is marked 100 and the worst state you can imagine is marked 0.

We would like you to indicate on this scale how good or bad your own health is **today**, in your opinion. Please do this by drawing a line from the box below to whichever point on the scale indicates how good or bad your health state is today.

Your own health state



Abbreviations: Tracheal Tube (TT), Intermittent Assisted Ventilation (IAV), Residual Urine Catheter (RUV)

SCIM – SPINAL CORD INDEPENDENCE MEASURE Version III

Self –Care

1. **Feeding** (cutting, opening containers, pouring, bringing food to mouth, holding cup with fluid)
   0. Need parenteral, gastrostomy or fully assisted oral feeding
   1. Need partial assistance for eating and/or drinking, or for wearing adaptive devices.
   2. Eat independently; needs adaptive devices or assistance only for cutting food and/or pouring and/or opening containers.
   3. Eat and drink independently; do not require assistance or adaptive devices.

2. **Bathing** (soaping, washing, drying body and head, manipulating water tap).

   A-Upper Body

   0. Require total assistance

   1. Require partial assistance
   2. Wash independently with adaptive devices or in a specific setting (e.g. bars, chair)
   3. Wash independently; do not require adaptive devices or a specific setting

   B-Lower Body

   0. Require total assistance

   1. Require partial assistance
   2. Wash independently with adaptive devices or in a specific setting
   3. Wash independently; do not require adaptive devices or a specific setting

3. **Dressing** (clothes, shoes, permanent orthoses: dressing, wearing, undressing).

   A-Upper Body

   0. Require total assistance

   1. Require partial assistance with clothes without buttons, zippers or laces

2. Independent with clothes without buttons, zippers or laces; require adaptive devices and/or specific setting
3. Independent with clothes without buttons, zippers or laces; do not require adaptive devices and/or specific setting; need assistance or adaptive devices and/or specific setting only for buttons, zippers or laces
4. Dress (any clothes) independently; do not require adaptive devices or specific setting.

B-Lower Body

0. Require total assistance

1. Require partial assistance with clothes without buttons, zippers or laces
2. Independent with clothes without buttons, zippers or laces; require adaptive devices and/or specific setting
3. Independent with cwobzl; do not require clothes without buttons, zippers or laces; need assistance or clothes without buttons, zippers or laces only for buttons, zippers or laces
4. Dress (any clothes) independently; do not require adaptive devices or specific setting.

4. Grooming (Washing hands and face, brushing teeth, combing hair, shaving, applying makeup)

0. Require total assistance
1. Require partial assistance
2. Groom independently with adaptive devices
3. Groom independently without adaptive devices

Respiration and Sphincter Management

1. Respiration

0. Require tracheal tube (TT) and permanent or intermittent assisted ventilation (IAV)
2. Breath independently with TT; require oxygen, much assistance in coughing or TT management
4. Breath independently with TT; require little assistance in coughing or TT management
6. Breath independently without TT; require oxygen much assistance in coughing or TT management
8. Breath without TT; require little assistance or stimulation for coughing
10. Breath independently without assistance or device

Abbreviations: Tracheal Tube (TT), Intermittent Assisted Ventilation (IAV), Residual Urine Catheter (RUV)

6. Sphincter Management – Bladder

0. Indwelling catheter
3. Residual urine volume (RUV) >100cc; no regular catheterization or assisted intermittent catheterization
6. RUV<100cc or intermittent self-catheterization; need assistance for applying drainage instrument
9. Intermittent self-catheterization; use external drainage instrument; do not need assistance for applying
11. Intermittent self-catheterization; continent between catheterization; do not use external drainage instrument
13. RUV<100cc; need only external urine drainage; no assistance is required for drainage
15. RUV <100cc; do not use external drainage instrument

7. Sphincter Management - Bowel

0. Irregular timing or very low frequency (less than once in 3 days) of bowel movements
5. Regular timing, but require assistance (e.g. for applying suppository); rare accidents (less than once a month)
8. Regular bowel movements, without assistance; rare accidents (less than once a month)
10. Regular bowel movements, without assistance; no accidents

Abbreviations: Tracheal Tube (TT), Intermittent Assisted Ventilation (IAV), Residual Urine Catheter (RUV)

8. Use of Toilet (perineal hygiene, adjustment of clothes before/after, use of napkins or diapers)

0. Require total assistance
1. Require partial assistance; do not clean self
2. Require partial assistance; clean self independently
4. Use toilet independently in all tasks but need adaptive devices or special setting (e.g. bars)
5. Use toilet independently; do not require adaptive devices or special setting

Mobility (room and toilet)

9. Mobility in Bed and Action to Prevent Pressure Sores

0. Need assistance in all activities; turning upper body in bed; turning lower body in bed, sitting up in bed, doing push-ups in wheelchair, with or without adaptive devices, but not with electric aides
2. Perform one of the activities without assistance
4. Perform two or three of the activities without assistance
6. Perform all the bed mobility and pressure release activities independently

10. Transfers: bed-wheelchair (locking wheelchair, lifting footrests, removing and adjusting arm rest, transferring, lifting feet)

0. Require total assistance
1. Need partial assistance and/or supervision, and/or adaptive devices (e.g. sliding board)
2. Independent (or do not require wheelchair)

11. Transfers: wheelchair – toilet – tub (if use toilet wheelchair: transfer to and from; if use regular wheelchair: locking wheelchair, lifting footrests, removing and adjusting armrests, transferring, lifting feet)

0. Require total assistance
1. Need partial assistance and/or supervision, and/or adaptive device (e.g. grab-bars)
2. Independent (or do not require wheelchair)

Abbreviations: Tracheal Tube (TT), Intermittent Assisted Ventilation (IAV), Residual Urine Catheter (RUV)

Mobility (indoors and outdoors, or even surface)

12. Mobility Indoors

0. Require total assistance
1. Need electric wheelchair or partial assistance to operate manual wheelchair
2. Move independently in manual wheelchair
3. Require supervision while walking (with or without devices)
4. Walk with a walking frame or crutches (swing)
5. Walk with crutches or two canes (reciprocal walking)
6. Walk with one cane
7. Need leg orthosis only
8. Walk without walking aids

13. Mobility for Moderate Distances (10 – 100 metres)

0. Require total assistance
1. Need electric wheelchair or partial assistance to operate manual wheelchair
2. Move independently in manual wheelchair
3. Require supervision while walking (with or without devices)
4. Walk with a walking frame or crutches (swing)
5. Walk with crutches or two canes (reciprocal walking)
6. Walk with one cane
7. Need leg orthosis only
8. Walk without aids

14. Mobility Outdoors (more than 100 metres)

0. Require total assistance
1. Need electric wheelchair or partial assistance to operate manual wheelchair
2. Move independently in manual wheelchair
3. Require supervision while walking (with or without devices)
4. Walk with a walking frame or crutches (swing)
5. Walk with crutches or two canes (reciprocal walking)
6. Walk with one cane
7. Need leg orthosis only
8. Walk without aids

15. Stair Management

0. Unable to ascend or descend stairs
1. Ascend and descent at least 3 steps with support or supervision of another person
2. Ascend and descent at least 3 steps with support of handrail and/or crutch or cane
3. Ascend and descend at least 3 steps without any support or supervision

16. Transfers: Wheelchair – car (approaching car, locking wheelchair, removing arm- and footrests, transferring to and from car, bringing wheelchair into and out of car)

0. Require total assistance
1. Need partial assistance and/or supervision and/or adaptive devices
2. Transfer independent; do not require adaptive devices (or do not require wheelchair)

17. Transfer: ground – wheelchair

0. Require assistance
1. Transfer independent with or without adaptive devices (or do not require wheelchair)

Abbreviation: Spinal Cord Injury (SCI), National Health System (NHS), Transcutaneous Electrical Nerve Stimulation (TENS), *answer the question if applicable to you

Socio-demographic Information

This is the **final part** of the questionnaire booklet. This part contains three sections; the first section asks questions **about yourself**, at the beginning and the end of the questionnaire, the second about your **pain in general** and the third about **your LBP**. Please, answer the questions as accurately as possible.

Questions about yourself

1) What is your sex?

Male ❑ Female ❑

2) What is your date of birth _____/_____/_____

day month year

3) What is your mother tongue?

English ❑ French ❑ Spanish ❑ Arabic ❑ Greek ❑

Other ❑ (please state)_____

4) What is your ethnic group?

White		**Asian**	
United Kingdom (UK)	❑	Turkish	❑
West European – non UK	❑	Pakistani	❑
North European	❑	Indian	❑
Greek	❑	Chinese	❑

East European – non Greek ❑ Japanese ❑

Mediterranean – non Greek ❑ Other Asian ❑

Other white ❑

Mixed **Black**

White and Black Caribbean ❑ Caribbean ❑

White and Black African ❑ African ❑

White and Asian ❑ Other Black ❑

Other Mixed ❑

5) What is the highest diploma/ degree you have earned?

High school ❑ Masters ❑

College or equivalent ❑ PhD or equivalent ❑

University Bachelor degree ❑

I have not earned any diploma/ degree ❑

Other ❑ (please state)_____

6) What is your marital status?

Single ❑ Living with partner ❑ Married ❑

Widowed ❑ Separated/ Divorced ❑ In a relationship ❑

Other (please state)_____

Abbreviation: Spinal Cord Injury (SCI), National Health System (NHS), Transcutaneous Electrical Nerve Stimulation (TENS), *answer the question if applicable to you

7) ***Which of the following best describes your main activity?

Self-employed ❑

Employed ❑

Voluntary work ❑

Working from home ❑

Receive health benefits ❑

Unemployed but was working before my SCI ❑

Unemployed and have never had a paid job ❑

Unable to work due to my SCI ❑

Looking for a job ❑

A homemaker ❑

Retired ❑

Student ❑

Other ❑ (please state)_____

8) Where do you live?

City/ town or village_____ County_____

9) What is the mile distance between your house and the nearest of the following. Please, if you do not know, please leave blank.

Hospital_____Mile(s)

SCI Rehabilitation Centre_____Mile(s)

SCI Outpatients' Specialist Unit_____Mile(s)

NHS Physiotherapy Unit_____Mile(s)

Private Physiotherapy_____Mile(s)

Pain clinic_____Mile(s)

Therapeutic Horse Riding Centre _____Mile(s)

Other centre of my interest_____Mile(s)

If "*other centre*", please state what type of centre

_____

10) *When did you have your SCI? _____/_____/_____

day month year

11) *What was the cause of your SCI?

Traumatic ❑(please, continue with questions below)

Non-traumatic ❑ (please, go to question 13, page 15)

Abbreviation: Spinal Cord Injury (SCI), National Health System (NHS), Transcutaneous Electrical Nerve Stimulation (TENS), *answer the question if applicable to you

12) *The cause of my traumatic SCI was

Road Traffic Accident

Bicycle Accident ❑
Assault ❑

Car Road Traffic Accident ❑
Gunshot ❑

Motorbike Road Traffic Accident ❑
Knife attack ❑

Pedestrian ❑
Other ❑

Other ❑

Violence Accident

Work related accident		Domestic related accident	
Falling of ladders/stairs	❑	Falling of stairs	❑
Falling of scaffolding	❑	Falling out of the window	❑
Slippery floor	❑	Slippery floor	❑
Tripping over object on the floor	❑	Tripping over object on the floor	❑
Other	❑	Other	❑

Sport accident

Car racing	❑	Horse riding	❑
Climbing	❑	Motorbike racing	❑
Cycling	❑	Rugby	❑
Diving	❑	Swimming	❑
Football	❑	Other	❑

If “other” please state_____

Abbreviation: Spinal Cord Injury (SCI), National Health System (NHS), Transcutaneous Electrical Nerve Stimulation (TENS), *answer the question if applicable to you

13) *The cause of my non-traumatic SCI was

Vascular

Atherosclerosis leading to loss of blood supply ❑

Embolism ❑

Epidural Haemorrhage ❑

Severe hypotension leading to loss of blood supply ❑

Other ❑

Cancerous (Neoplastic)

Cancer of the in and around spinal structures, e.g. meningioma, glioma etc ❑

Cancer spread from another site, e.g. lung, breast, prostate etc ❑

Other ❑

Inflammation and infections

Epidural abscess ❑

Sarcoidosis ❑

Transverse myelitis ❑

Tuberculosis ❑

Other ❑

Degenerative

Osteoarthritis ❑

Osteoporosis ❑

Paget's Disease ❑

Rheumatoid Arthritis ❑

Spondylolisis ❑

Other ❑

Spinal deformity

Kyphosis ❑

Kypholordosis ❑

Kyphoscoliosis ❑

Lordosis ❑

Scoliosis ❑

Spinal bifida ❑

Other neurological

Cerebral Palsy ❑

Friedreich's ataxia ❑

Multiple Sclerosis ❑

Other ❑

Abbreviations: Tracheal Tube (TT), Intermittent Assisted Ventilation (IAV), Residual Urine Catheter (RUV)

Other ❑

If "*other*" please state_____

14) ***What is the level of your injury? (Please, state the number of vertebra)

Cervical are the first 7 vertebrae of the spine; known as C1 to C7
Thoracic (upper back) are the next 12 vertebrae; known as T1 to T12
Lumbar (lower back) are the next 5 vertebrae; know as L1 to L5

The level of my injury is

Cervical_____ Thoracic_____ Lumbar_____

15) ***What is the type of your SCI?

Complete paraplegia ❑ Complete tetraplegia ❑

Incomplete paraplegia ❑ Incomplete tetraplegia ❑

I don't know ❑

Other ❑ (please state)_____

16) What type of health insurance do you have?

NHS ❑ Private ❑ Both ❑

Other (please state)_____

Abbreviations: Tracheal Tube (TT), Intermittent Assisted Ventilation (IAV), Residual Urine Catheter (RUV)

17) Which insurance have you mainly used for your various SCI related treatments?

NHS ❑ Private ❑ Both ❑

Other (please state)_____

18) Where were you first treated for your SCI?

NHS hospital	❑	Private rehabilitation centre	❑
Private hospital	❑	NHS SCI centre	❑
NHS rehabilitation centre	❑	Private SCI centre	❑

Other (please state)_____

19) In which country were you first treated for your SCI?

UK ❑

Other ❑ (please state)_____

20) How long did you stay in the above hospital/ centre after your SCI?

If you were then transferred to another unit (e.g. SCI centre) please also state how long you stayed there.
(Please, state if months or weeks)

Initial hospital/centre for _____

Transferred to other unit for_____

Abbreviations: Tracheal Tube (TT), Intermittent Assisted Ventilation (IAV), Residual Urine Catheter (RUV)

21) Have you had any surgery after your SCI?

No ❑

Yes ❑ (please, state what surgery you have had)

I have had_____

_____

22) Do your friends and family support you with your SCI?

Yes	❑	I don't want their support	❑
No	❑	I don't need their support	❑
Not as much as I need	❑	I don't want to say	❑

Other (please state)_____

Questions about your pain in general

23) *Since you got your SCI have you ever felt any pain?

Yes ❑ (please, continue with questions below)

No ❑ (please go to question 39, page 21)

24) *How long after your SCI did your pain start?

Immediately after the SCI	❑	Between 2 weeks and 1 month	❑
The next day	❑	Between 1 - 3 months	❑
After 3 days	❑	Between 3 - 6 months	❑

After 1 week ❑ Between 6 months and 1 year ❑

After 2 weeks ❑ After 1 year ❑

Other ❑ (please state)_____

25) *On average over the last 6 months how many days of each month did you feel pain?

1 - 4 days ❑ 21 - 25 days ❑

5 - 9 days ❑ 26 - 30 days ❑

10 -15 days ❑ Every day ❑

16 - 20 days ❑

If pain first appeared less than 6 months ago, please state how long ago it appeared

_____

26) *What type of pain do you suffer from? Please, tick all that apply.

Neuropathic above level of injury ❑ Upper limb ❑

Neuropathic at level of injury ❑ Musculoskeletal ❑

Neuropathic below level of injury ❑ Back pain ❑

I don't know ❑

Other ❑ (please state)_____

27) *Do you take any medication for your pain?

Yes ❑ (please, continue with questions below)

No ❑ (please, go to question 30 below)

Abbreviation: Spinal Cord Injury (SCI), National Health System (NHS), Transcutaneous Electrical Nerve Stimulation (TENS), *answer the question if applicable to you

28) How often do you take pain medication?

Every day ❑ Whenever I have pain ❑

On a regular basis ❑

Other ❑ (please state)_____

29) When you take pain medication, how many hours does it usually take before the pain returns?

1 hour ❑ 4 hours ❑

2 hours ❑ 5-12 hours ❑

3 hours ❑ More than 12 hours ❑

Pain medication does not help ❑

30) ***While in the hospital/ centre**, were you assessed by the health professionals for your pain? Please, tick all that apply.

Yes, I was assessed by a doctor immediately ❑

Yes, I was assessed by a nurse immediately ❑

Yes, I was assessed by a physiotherapist immediately ❑

I was assessed by a doctor but only after I complained of my pain ❑

I was assessed by a nurse but only after I complained of my pain ❑

I was assessed by a physiotherapist but only after I complained of my pain ❑

I was assessed long time after my pain started ❑

No, I was not assessed by anyone for my pain ❑

I did not feel any pain while in the hospital/centre ❑

Other ❑ (please state)_____

Abbreviation: Spinal Cord Injury (SCI), National Health System (NHS), Transcutaneous Electrical Nerve Stimulation (TENS), *answer the question if applicable to you

31) ***While in the hospital** what **pain** treatment did you have? Please, state all that apply.

Pain medication ❑ Acupuncture ❑

Physiotherapy ❑ Kinesiotherapy ❑

Cold Therapy ❑ Massage ❑

Heat Therapy ❑ Strengthening exercises ❑

TENS ❑ I did not feel any pain while in the hospital/centre ❑

Relaxation techniques❑ I felt pain but I was not offered any therapy ❑

Electrotherapy ❑ I don't remember ❑

Other ❑ (please state)_____

32) **While in the hospital/centre**, how often did you have pain treatment?

Not applicable ❑

Pain medication_____

Physiotherapy_____

Cold Therapy_____

Heat Therapy_____

TENS_____

Relaxation techniques_____

Electrotherapy_____

Acupuncture_____

Kinesiotherapy _____

Massage_____

Strengthening exercises_____

Other (please state)_____

Abbreviations: Spinal Cord Injury (SCI), Low Back Pain (LBP), National Health System (NHS), Transcutaneous Electrical Nerve Stimulation (TENS), *answer the question if applicable to you

33) ***Since** you have **left the hospital/centre** have you had any pain treatment? Please, state all treatments that you have had.

Pain medication ❑
Physiotherapy ❑
Cold Therapy ❑
Heat Therapy ❑
TENS ❑
Relaxation techniques ❑
Electrotherapy ❑
Acupuncture ❑
Kinesiotherapy ❑
Massage ❑
Strengthening exercises ❑
Therapeutic horse riding ❑
I don't remember ❑
I did not feel any pain ❑
I felt pain but I was not offered any therapy ❑
Other ❑ (please state)_____

34) **Since** you have **left the hospital/centre**, how often did you have pain treatment?

Not applicable ❑
Pain medication_____
Physiotherapy_____
Cold Therapy_____
Heat Therapy_____
TENS_____
Relaxation techniques_____
Electrotherapy_____
Acupuncture_____
Kinesiotherapy _____
Massage_____
Strengthening exercises_____
Therapeutic horse riding_____
Other (please state)_____

Abbreviation: Spinal Cord Injury (SCI), National Health System (NHS), Transcutaneous Electrical Nerve Stimulation (TENS), *answer the question if applicable to you

35) ***If you had any pain treatment** which one do you believe has most helped you? If more than one, please rank them in order of effectiveness.

Not applicable ❑
Pain medication_____
Physiotherapy_____
Cold Therapy_____
Heat Therapy_____
TENS_____
Relaxation techniques_____
Electrotherapy_____
Acupuncture_____
Kinesiotherapy _____
Massage_____
Strengthening exercises_____
Therapeutic horse riding_____
Other (please state)_____

36) On **average**, since you have left the hospital/centre, how long were you on a **waiting list** to receive your pain treatment?

Treatment started immediately	❑	4 months	❑
1 – 2 weeks	❑	5 months	❑
1 month	❑	6 months	❑
2 months	❑	More than 6 months	❑
3 months	❑	I was not on a waiting list	❑

Other (please state)_____

Abbreviations: Spinal Cord Injury (SCI), Low Back Pain (LBP), National Health System (NHS), Transcutaneous Electrical Nerve Stimulation (TENS), *answer the question if applicable to you

37) *Have you had **pain free** period of **1 week or more** since your pain first started?

Yes, most of the time	❑	Yes, but rarely	❑
Yes, frequently	❑	No, I always have had pain	❑
Yes, sometimes	❑	I do not remember	❑
Yes, but not very often	❑		

38) *Do you feel any pain right **now**?

No ❑

Yes ❑ (please, describe it in a few words)

_____
_____
_____
_____
_____

Questions about your LBP

39) Since you got your SCI have you ever felt **Low Back Pain (LBP)**?

Yes ❑ (please, continue with questions below)

No ❑ (please, go to question 53, page 24)

40) *How long after your SCI did your **LBP** start?

Immediately after the SCI	❑	Between 2 weeks and one month	❑
The next day	❑	Between 1 - 3 months	❑
After 3 days	❑	Between 3 - 6 months	❑
After 1 week	❑	Between 6 months and 1 year	❑

Abbreviations: Spinal Cord Injury (SCI), Low Back Pain (LBP), National Health System (NHS), Transcutaneous Electrical Nerve Stimulation (TENS), *answer the question if applicable to you

After two weeks ❑ After 1 year ❑

Other ❑ (please state)_____

41) *On average over the last 6 months how many days of each month did you feel LBP?

1 - 4 days ❑ 21 - 25 days ❑

5 - 9 days ❑ 26 - 30 days ❑

10 - 15 days ❑ Every day ❑

16 - 20 days ❑

If LBP first appeared less than 6 months ago, please state how long ago it appeared.

_____

42) *Do you take any medication for your **LBP**?

Yes ❑ (please, continue with questions below)

No ❑ (please, go to question 45, page 22)

43) *How often do you take **LBP** medication?

Every day ❑ Whenever I have pain ❑

On a regular basis ❑

Other ❑ (please state)_____

Abbreviations: Spinal Cord Injury (SCI), Low Back Pain (LBP), National Health System (NHS), Transcutaneous Electrical Nerve Stimulation (TENS), *answer the question if applicable to you

44) When you take medication for your **LBP**, how many hours does it usually take before the LBP returns?

1 hour	❑	4 hours	❑
2 hours	❑	5-12 hours	❑
3 hours	❑	More than 12 hours	❑
		Pain medication does not help	❑

45) ***While in the hospital/centre**, were you assessed by the health professionals for your **LBP**? Please, tick all that apply.

Yes, I was assessed by a doctor immediately ❑
Yes, I was assessed by a nurse immediately ❑
Yes, I was assessed by a physiotherapist immediately ❑
I was assessed by a doctor but only after I complained of my pain ❑
I was assessed by a nurse but only after I complained of my pain ❑
I was assessed by a physiotherapist but only after I complained of my pain ❑
I was assessed long time after my pain started ❑
No, I was not assessed by anyone for my pain ❑
I did not feel any LBP while in the hospital/centre ❑

Other ❑ (please state)_____

Abbreviations: Spinal Cord Injury (SCI), Low Back Pain (LBP), National Health System (NHS), Transcutaneous Electrical Nerve Stimulation (TENS), *answer the question if applicable to you

46) ***While in the hospital** what **LBP** treatment did you have? (please, state all that apply)

Pain medication ❑ Acupuncture ❑
Physiotherapy ❑ Kinisiotherapy ❑
Cold Therapy ❑ Massage ❑
Heat Therapy ❑ Strengthening exercises ❑
TENS ❑ I did not feel any LBP while in the hospital/centre ❑
Relaxation techniques ❑ I felt LBP but I was not offered any therapy ❑
Electrotherapy ❑ I don't remember ❑
Other ❑ (please state)_____

47) **While in the hospital/centre**, how often did you have **LBP** treatment?

Not applicable ❑
Pain medication_____
Physiotherapy_____
Cold Therapy_____
Heat Therapy_____
TENS_____
Relaxation techniques_____
Electrotherapy_____
Acupuncture_____
Kenisiotherapy _____
Massage_____
Strengthening exercises_____
Other (please state)_____

Abbreviations: Spinal Cord Injury (SCI), Low Back Pain (LBP), National Health System (NHS), Transcutaneous Electrical Nerve Stimulation (TENS), *answer the question if applicable to you

48) ***Since** you have left the **hospital/centre** have you had any **LPB** treatment? Please, state all the treatments that you have had.

Pain medication	❑	Acupuncture	❑
Physiotherapy	❑	Kinesiotherapy	❑
Cold Therapy	❑	Massage	❑
Heat Therapy	❑	Strengthening exercises	❑
TENS	❑	Therapeutic horse riding	❑

Relaxation techniques❑ I have not felt any LBP while in the hospital/centre❑

Electrotherapy ❑ I have felt LBP but I was not offered any therapy❑

I don't remember❑

Other ❑ (please state)_____

49) **Since** you have **left the hospital/centre**, how often did you have **LBP** treatment?

Not applicable ❑

Pain medication_____

Physiotherapy_____

Cold Therapy_____

Heat Therapy_____

TENS_____

Relaxation techniques_____

Electrotherapy_____

Acupuncture_____

Kinesiotherapy _____

Massage_____

Strengthening exercises_____

Therapeutic horse riding_____

Other (please state)_____

Abbreviations: Spinal Cord Injury (SCI), Low Back Pain (LBP), *answer the question if applicable to you

50) ***If you had any LBP** treatment which one do you believe has most helped you? If more than one, please rank them in order of effectiveness.

Pain medication_____
Physiotherapy_____
Cold Therapy_____
Heat Therapy_____
TENS_____
Relaxation techniques_____
Electrotherapy_____
Acupuncture_____
Kinesiotherapy _____
Massage_____
Strengthening exercises_____
Therapeutic horse riding_____
Other (please state)_____

51) On **average**, since you have left the hospital/centre, how long were you on a **waiting list** to receive your **LBP** treatment?

Treatment started immediately ❑
1 – 2 weeks ❑
1 month ❑
2 months ❑
3 months ❑
4 months ❑
5 months ❑
6 months ❑
More than 6 months ❑
I was not on a waiting list ❑

Other (please state)_____

52) ***Have you had **LBP free** period of **1 week or more** since your LBP started?

Yes, most of the time ❑
Yes, frequently ❑
Yes, sometimes ❑
Yes, but not very often ❑
Yes, but rarely ❑
No, I always have had pain ❑
I do not remember ❑

Final questions about yourself

53) Do you have any visual problems?

Yes ❑ No ❑

If "*yes*", please state what type_____

54) Did you read the information sheet and questionnaire booklet on your own?

Yes ❑ No ❑

If "*no*", who helped you with the reading?

Please state_____

55) Do you have any problems with writing?

Yes ❑ No ❑

If "*yes*", please state what type_____

56) ***Did you manually fill in the questionnaire on your own, without the help of anyone else?

Yes ❑ (please, go to question 58 below)

No ❑ (please, continue with question 57 below)

57) *If someone else helped you with filling in the questionnaire, how did they help you?

I was answering all the questions but someone else was manually filling them in for me ❑

I was answering the questions but someone else manually filled in for me both the VAS and the body pain drawing ❑

I was answering the questions but someone else manually filled in for me only the VAS ❑

I was answering the questions but someone else manually filled in for me only the body pain drawing ❑

Other, please state_____

58) *Please, give the date when you completed this questionnaire

___/___/200___

Thank you very much for taking the time to complete this questionnaire

Return slip (optional)

Please, give us your name and address so we can identify your returned questionnaire in case you need us to do so, or contact you regarding this or future studies if agreed by you.

Name_____

Address_____

Post Code_____

Contact number_____

Email address (if applicable)_____

In the future, would you like to be contacted and informed about our study programs and research?

Yes ❑ No ❑

Thank you very much for taking the time to complete this questionnaire

Appendix 3; Questionnaire in Greek

Supplement to Chapters 4 and 5

Πληροφορίες προς συμμετέχοντες ενήλικες με Κάκωση Νωτιαίου Μυελού

Αγαπητέ Κύριε/ Κυρία

Τίτλος έρευνας: "Η μελέτης της εμπειρίας του πόνου, η ένταση και η επίδρασή της στις ζωές των ατόμων με Κάκωση Νωτιαίου Μυελού (ΚΝΜ) στις Ηνωμένες Πολιτείες Αμερικής (ΗΠΑ), στο Ηνωμένο Βασίλειο (ΗΒ) και την Ελλάδα".

Πρόσκληση

Σας προσκαλούμε να πάρετε μέρος σε μία ερευνητική μελέτη. Πριν αποφασίσετε είναι απαραίτητο να καταλάβετε γιατί γίνεται αυτή η έρευνα και τι θα συμπεριλάβει. Παρακαλώ, διαβάστε τις παρακάτω πληροφορίες προσεχτικά και συζητήστε το με άλλους εάν το θέλετε.

- Το πρώτο μέρος σας λέει για την μελέτη και τι θα γίνει σε εσάς εάν πάρετε μέρος.
- Το δεύτερο μέρος σας δίνει περισσότερες λεπτομέρειες για την μελέτη.

Ρωτήστε με εάν κάτι δεν είναι ξεκάθαρο ή εάν θα θέλατε περισσότερες πλήροφορίες. Πάρτε το χρόνο σας για να αποφασίσετε εάν θέλετε να συμμετάσχετε.

Ποιός είναι ο σκοπός της έρευνας;

Ο σκοπός της έρευνας είναι να μελετήσει τον πόνο γενικά και τον πόνο στη μέση (οσφυαλγία) ειδικά σε άτομα με Κακωση Νωτιαίου Μυελού (ΚΝΜ). Θα διερευνηθεί η εμπειρία του πόνου και πως αυτή μπορεί να επηρεάσει την ποιότητα ζωής και την λειτουργικότητα. Τελός, θα μελετηθούν τα διαφορετικά συστήματα υγείας και οι πολιτισμικές επιρροές και πως αυτά μπορούν να

επηρεάσουν τον πόνο καθώς η έρευνα θα διεξαχθεί στη Ελλάδα, στις ΗΠΑ και στο Ηνωμένο Βασίλειο.

Γιατί Επιλέχθηκα;

Επιλεχθήκατε γιατί έχετε ΚΝΜ και μπορεί να εκπληρώνετε τα κριτήρια συμμετοχής αυτής της έρευνας. Συνολικά τουλάχιστον 185 άτομα με ΚΝΜ που ζούνε στις ΗΠΑ, στο Ηνωμένο Βασίλειο και την Ελλάδα θα συμμετάσχουν σε αυτή την έρευνα.

Πώς αναγωρίστηκα;

Αναγνωριστήκατε μέσω του “Αναπηρία Τώρα”. Λόγο της προστασίας των προσωπικών δεδομένων δεν μπορώ να έχω άμεση πρόσβαση στα προσωπικά σας στοιχεία για να επικοινωνήσω μαζί σας. Για τον λόγο αυτό το “Αναπηρία Τώρα” προσκλήθηκε να συμμετάσχει στην μελέτη αυτή. Το “Αναπηρία Τώρα” ενέκρινε την μελέτη και ένας τοπικός συνεργάτης ορίστηκε και συμφώνησε να προωθήσει αυτό το ερωτηματολόγιο σε εσάς στον διαδύκτιο ή μέσω email.

Πρέπει να πάρω μέρος;

Όχι, εξαρτάται από εσάς αν θα αποφασίσετε να πάρετε μέρος ή όχι. Εάν αποφασίσετε να πάρετε μέρος έχετε την επιλογή να απαντήσετε στο ερωτηματολόγιο ανώνυμα. Εάν αποφασίσετε να μας δώσετε το όνομα σας, σας βεβαιώνουμε ότι όλες οι προσωπικές σας πληροφορίες θα χειρισθούν με απόλυτη εμπιστευτικότητα. Η απόφαση σας να μην συμμετάσχετε δεν θα επηρεάσει καθόλου την θεραπεία που λαμβάνετε.

Τι είδος μελέτης είναι;

Αυτή η μελέτη είναι μέρος ενός μεγαλύτερου διδακτορικού προγράματος το οποίο μελετάει τον πόνο γενικότερα και την οσφυαλγία ειδικότερα σε ενήλικες με ΚΝΜ και παιδιά με Εγκεφαλική Παράλυση. Ένας από τους σκοπούς του συνολικού διδακτορικού είναι να μελετήσει πως μία συγκεκριμένη θεραπεία που βασίζεται στην τρισδιάστατη κίνηση μπορεί να οφελήσει την οσφυαλγία, στάση, ισορροπία, λειτουργικότητα, και την ποιότητα ζωής σε αυτούς τους πληθυσμούς.

Το παρόν μέρος του σχεδίου, στο οποίο προσκαλείστε να συμμετάσχετε, αποτελείται από ένα αυτο-συμπληρώμενο ερωτηματολόγιο, το οποίο εσωκλείεται σε αυτό το γράμμα, με στόχο να συμπληρωθεί μόνο από άτομα με

ΚΝΜ. Στο δεύτερο μέρος αυτού του γράμματος θα βρείτε λεπτομέρειες ως προς το πως να συμπληρώσετε το ερωτηματολόγιο.

Ποια είναι τα πιθανά ωφέλη από την συμμετοχή μου;

Ο πόνος έχει βρεθεί να είναι μέρος της καθημερινής ζωής σε άτομα με ΚΝΜ και σε αρκετές καταστάσεις μπορεί να προκαλέσει στρες και ανησυχία, να επηρεάσει την ποιότητα ζωής και να παρέμβει στις δραστηριότητες καθημερινής ζωής. Παρ' όλα αυτά, η εμπειρία του πόνου γενικά και η οσφυαλγία συγκεκριμένα δεν έχουν μελετηθεί αρκετά σε άτομα με ΚΝΜ.

Αναμένεται ότι θα έχετε έμμεσα κέρδη από την συμμετοχή σας διότι τα αποτελέσματα της έρευνας αυτής θα χρησιμοποιηθούν για την ανάλυση ερωτήσεων σχετικές με τον πόνο που μπορούν να συμβάλουν στον να εγείρουν ενημερότητα και να προκαλέσουν περαιτέρω μελέτες με σκοπό την βελτίωση των συμπτωμάτων πόνου, της ποιότητας ζωής και της λειτουργικότητας σε άτομα με ΚΝΜ και πόνο.

Τι θα μου συμβεί εάν αποφασίσω να πάρω μέρος;

Το μόνο που έχετε να κάνετε είναι να απαντήσετε στο ένθετο ερωτηματολόγιο και να το επιστρέψετε σε εμένα.

Θα χρειαστεί να πληρώσω κάτι;

Όχι, δεν θα χρειαστεί να πληρώσετε τίποτα.

Υπάρχουν κάποια ρίσκα;

Δεν υπάρχουν ενδεχόμενα ρίσκα ως αποτέλεσμα της συμφωνίας σας να συμπληρώσετε το ερωτηματολόγιο.

Τι συμβαίνει εάν δεν έχω οσφυαλγία ή άλλο πόνο;

Είναι πολύ σημαντικό να απαντήσετε στο ερωτηματολόγιο ακόμα και εάν δεν έχετε οσφυαλγία ή άλλο πόνο. Θα μας δώσετε έτσι πολύτιμες πληροφορίες σχετικά με το ποσοστό του πόνου και της οσφυαλγίας σε ΚΝΜ και θα μας βοηθήσετε στην στατιστική σύγκριση μεταξύ ατόμων που έχουν με αυτούς που δεν έχουν οσφυαλγία και πόνο. Ανάλογα με τις απαντήσεις που θα επιλέξετε θα κατευθυνθήτε και στις ανάλογες ερωτήσεις.

Τι θα γίνει εάν υπάρξει κάποιο πρόβλημα;

Κανένα πρόβλημα δεν αναμένεται να υπάρξει, παρόλα αυτά εάν αυτό συμβεί, θα συζητηθεί μαζί σας.

Η συμμετοχή μου θα παραμείνει εμπιστευτική;

Ναι. Το όνομα και η διεύθυνσή σας θα αφαιρεθούν από κάθε δεδομένο και δεν θα μπορείτε να αναγνωριστήτε από αυτό. Όλα τα δεδομένα θα κρατούνται σε κλειδωμένο ντουλάπι, που βρίσκεται στο Πανεπιστήμιο, και μόνο εγώ θα έχω πρόσβαση σε αυτά.

Σας ευχαριστούμε που διαβάσατε μέχρι εδώ – εάν εξακολουθείτε να ενδιαφέρεστε, παρακαλώ πηγαίνετε στο δεύτερο μέρος.

Μέρος δεύτερο

Τι θα συμβεί αν δε θέλω να συνεχίσω με την έρευνα;

Αν αποφασίσετε να πάρετε μέρος, μπορείτε να αποχωρήσετε οποιαδήποτε στιγμή, και χωρίς να αιτιολογηθείτε. Η απόφαση να αποσυρθείτε δε θα επηρεάσει την φροντίδα που λαμβάνετε. Ωστόσο, θα είναι αδύνατον να αποσυρθούν ερωτηματολόγια τα οποία έχουν επιστραφεί ανώνυμα αφού δεν θα είναι δυνατόν να αναγνωριστεί από ποιον έχουν συμπληρωθεί.

Τι θα συμβεί αν θέλω να παραπονεθώ για κάτι;

Αν έχετε κάποια αμφιβολία για κάποιο τμήμα της έρευνας, θα πρέπει να ζητήσετε να μιλήσετε με τους ερευνητές οι οποίοι θα προσπαθήσουν να απαντήσουν στις ερωτήσεις σας όσο το δυνατόν καλύτερα. Μπορείτε να επικοινωνήσετε μαζί μου. Αν παραμένετε ανικανοποίητος/-η και επιθυμείτε να παραπονεθείτε επίσημα, μπορείτε να αποτανθείτε στους υπεύθυνους αυτής της έρευνας. Τα τηλέφωνά τους βρίσκονται στο τέλος αυτού του φυλλαδίου.

Θα ενημερωθεί ο γιατρός μου;

Όχι, ο γιατρός σας δεν θα ενημερωθεί. Ωστόσο, αν κατά τη διάρκεια της έρευνας κριθεί σκόπιμο να ενημερωθεί ο γιατρός σας θα ζητηθεί η συγκατάθεσή σας εκ των προτέρων γι'αυτό.

Τι θα συμβεί με τα αποτελέσματα αυτής της έρευνας;

Τα αποτελέσματα αυτής της έρευνας θα συμπεριληφθούν στο διδακτορικό μου μέσα στα επόμενα δύο χρόνια. Επιπρόσθετα, θα δημοσιευθούν κατά τα χρόνια που θα ακολουθήσουν την ολοκλήρωση του διδακτορικού. Εάν επιθυμείτε, θα μπορούσα να σας στείλω μία αναφορά με τα αποτελέσματα ή θα μπορούσατε να τα βρείτε απευθείας απο τα επιστημονικά περιοδικά όταν θα έχουν δημοσιευθεί. Σε καμμία περίπτωση το όνομά σας δεν πρόκειται να δημοσιευθεί σε κάποια αναφορά ή δημοσίευση.

Ποιος οργανώνει και χρηματοδοτεί την έρευνα;

Η έρευνα υποστηρίζεται από τη Σχολή Επιστημών Υγείας και Κοινωνικής Πρόνοιας (ΣΕΥΠ) του Πανεπιστημίου Μπρουνέλ του Δυτικού Λονδίνου, και χρηματοδοτείται μερικώς από το Ερευνητικό Συμβούλιο Μηχανικών και Φυσικών Επιστημών και τη Σχολή αποφοίτων του Μπρουνέλ. Προϊστάμενοι σε αυτή την έρευνα είναι οι καθηγητές κ.κ. Lorraine DeSouza και Ian Sutherland.

Ποιος έχει επιθεωρήσει την έρευνα;

Προτού οποιαδήποτε έρευνα μπορέσει να προχωρήσει πρέπει να επιθεωρηθεί και να εγκριθεί από μία Επιτροπή Ηθικής Δεοντολογίας. Ο σκοπός είναι η επιβεβαίωση ότι η έρευνα είναι έτοιμη να ξεκινήσει. Η συγκεκριμένη έρευνα έχει μελετηθεί και εγκριθεί από την Επιτροπή Ηθικής Δεοντολογίας της ΣΕΥΠ του Πανεπιστημίου Μπρουνέλ. Το "Αναπηρία τώρα" έχει επίσης μελετήσει την έρευνα και εγκρίνει την συνεργασία.

Πόσο χρόνο θα μου πάρει να συμπληρώσω το ερωτηματολόγιο και από τι αποτελείται αυτό;

Θα σας πάρει περίπου 1 ώρα για να συμπληρώσετε το ερωτηματολόγιο. Αντιλαμβανόμαστε ότι αυτό το ερωτηματολόγιο ίσως χρειάζετε χρόνο για να συμπληρωθεί αλλά εξετάζει δεδομένα τα οποία στο παρελθόν δεν εξετάστηκαν σε τέτοιο βάθος και οι πληροφορίες που θα συλλεχθούν θα παρουσιάσουν ιδιαίτερο ενδιαφέρον. Εάν θέλετε συμπληρώσετε το ερωτηματολόγιο τμηματικά.

Το πρώτο μέρος αποτελείται από 3 σταθμισμένα ερωτηματολόγια. Αυτά είναι η σύντομη μορφή ερωτηματολογίου του πόνου του ΜακΓκίλλ, το EQ-5D και το Μ.Α.Νω.Μυ.

Η σύντομη μορφή του ερωτηματολογίου του ΜακΓκίλλ εξετάζει τον πόνο και τις διαστάσεις του. Έχει συμπεριληφθεί και ένα διάγραμμα σωματικού πόνου πάνω στο οποίο μπορείτε να σημειώσετε τις περιοχές στο σώμα σας που νοιώθετε πόνο. Η ένταση του πόνου υπολογίζεται με την οπτική αναλογική κλίμακα (ΟΑΚ). Επίσης, υπάρχει μία λίστα από περιγραφικές λέξεις που παρέχει αισθητήριες, συναισθηματικές και πληροφορίες αποτίμησης για τον πόνο σας.

Το ερωτηματολόγιο EQ-5D μετράει την ποιότητα ζωής και παρέχει πληροφορίες σχετικά με την κινητικότητα, αυτοεξηπηρέτηση, συνήθεις δραστηριότητες, πόνο/ δυσφορία και άγχος/θλίψη.

Το Μ.Α.Νω.Μυ παρέχει πληροφορίες σχετικά με την λειτουργικότητα. Μελετάει την αυτοεξυπηρέτηση, το αναπνευστικό, τον έλεγχο του σφιγκτήρα και την κινητικότητα σε εσωτερικό και εξωτερικό χώρο.

Το δεύτερο μέρος του ερωτηματολογίου αποτελείται από κοινωνικο-δημογραφικές ερωτήσεις με σκοπό να συλλέξει πληροφορίες σχετικές με το ιστορικό και την θεραπεία της ΚΝΜ σας, και αν και πως αυτά σχετίζονται με την παρουσία ή όχι πόνου και οσφυαλγίας. Αυτό το μέρος του ερωτηματολογίου μπορεί να βοηθήσει να προσδιορίσουμε τις καλύτερες θεραπευτικές επιλογές.

Θέλω να συμμετάσχω. Τι κάνω τώρα;

Εάν συμφωνήσετε να συμμετάσχετε αλλά επιθυμείτε να παραμείνετε ανώνυμος/-η, παρακαλώ συμπληρώστε και επιστρέψτε το ερωτηματολόγιο χωρίς να γράψετε το όνομα σας πουθενά. Το συμπληρωμένο ερωτηματολόγιο θα επιστραφεί κατευθείαν σε εμένα, την κύρια ερευνήτρια της μελέτης. Παρακαλώ χρησιμοποιήστε τον φάκκελο επιστροφής που σας έχουμε συμπεριλάβει σε αυτό το γράμμα.

Θέλω να συμμετάσχω αλλά δεν μπορώ να συμπληρώσω μόνος/η το ερωτηματολόγιο.

Αν αντιμετωπίζετε δυσκολίες στην ανάγνωση ή συμπλήρωση αυτού του ερωτηματολογίου, παρακαλώ ζητήστε βοήθεια από κάποιο μέλος της οικογένειας σας ή φίλο. Όμως, παρακαλώ επιβεβαιώστε ότι εσείς απαντάτε στις ερωτήσεις και ότι σας βοηθούν με το να τις γράψουν στο γραπτό ερωτηματολόγιο. Όταν συμπληρώνετε την ΟΑΚ και το διάγραμμα σωματικού πόνου, παρακαλώ δείξτε τους με όσο το δυνατόν μεγαλύτερη ακρίβεια που ακριβώς είναι η απάντηση σας.

Εάν χρειάζεστε επιπλέον βοήθεια, παρακαλώ επικοινωνήστε μαζί μου.

Μπορώ να το κάνω αργότερα;

Ναι. Το ερωτηματολόγιο θα παραμείνει στο διαδίκτυο για τουλάχιστον ένα μήνα.

Δεν θέλω να συμμετάσχω. Τι κάνω τώρα;

Εάν δεν θέλετε να συμμετάσχετε, παρακαλώ αγνοήστε αυτό το γράμμα. Υπάρχει η πιθανότητα να παραλάβετε ένα αυτόματο γράμμα υπενθύμησης στο μέλλον. Εάν και τότε εξακολουθείτε να μην θέλετε να συμμετάσχετε παρακαλώ αγνοήστε και εκείνο το γράμμα. Όμως κάθε πληροφορία που μας παρέχετε θα είναι ιδιαίτερα χρήσιμη.

Σας ευχαριστούμε πάρα πολύ για τον χρόνο που διαθέσατε να διαβάσετε αυτό το ενημερωτικό. Εάν έχετε περαιτέρω ερωτήσεις, παρακαλώ επικοινωνήστε μαζί μου ελεύθερα. Εάν θέλετε να παραμείνετε ανώνυμος/-η σε εμένα αλλά θα θέλατε περαιτέρω πληροφορίες παρακαλώ επικοινωνήστε με το “Αναπηρία Τώρα”.

Εάν θέλετε να μάθετε περισσότερα σχετικά με πόνο στην ΚΝΜ παρακαλώ πηγαίνετε στην ιστοσελίδα του "Αναπηρία Τώρα". Η ιστοσελίδα είναι: www.DISABLED.GR

Με εκτίμηση

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Σας ευχαριστούμε πάρα πολύ που διαβάσατε το ενημερωτικό γράμμ

Για χρήση γραφείου μόνο:

Ημερομηνία συμπλήρωσης ερωτηματολογίου	
Ημερομηνία ανάλυσης ερωτηματολογίου	
Κωδικός αναγνώρισης ερωτηματολογίου	
Κωδικός αναγνώρισης κέντρου	
Κωδικός αναγνώρισης συμμετέχοντα	
Χώρα προέλευσης	

:

Σας είμαστε ευγνώμων για την βοήθεια σας στην συμπλήρωση των παρακάτω ερωτήσεων. Οι πληροφορίες που θα μας δώσετε θα μας βοηθήσουν να καταλάβουμε περισσότερα πράγματα για την κάκωση νωτιαίου μυελού και τα συμπτώματα γύρω από αυτήν. Η ανάλυση των αποτελεσμάτων μπορεί να μας βοηθήσει στην ανάπτυξη μελλοντικών θεραπειών με στόχο την καλυτέρευση του πόνου και της ποιότητας ζωής σε άτομα με κάκωση νωτιαίου μυελού.

Δεν υπάρχουν **σωστές** ή **λάθος** απαντήσεις στις ερωτήσεις αυτές. Μας ενδιαφέρουν οι **προσωπικές** απόψεις και όχι αυτές της οικογένειας σας ή των θεραπευτών σας.

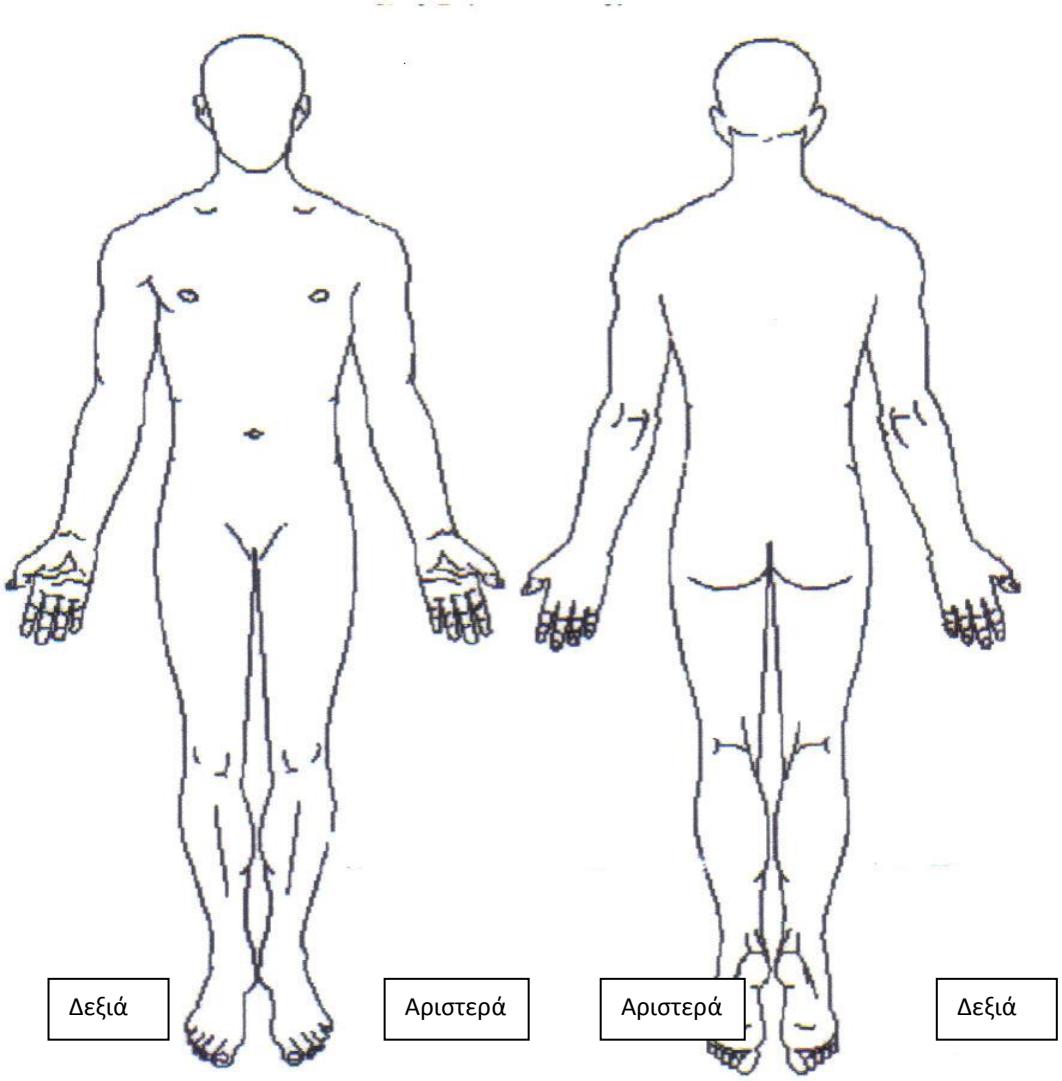
- **Θα θέλαμε να απαντήσετε στις ερωτήσεις όσο πιο ειλικρινά και γρήγορα γίνετε.**
- **Εάν δυσκολεύεστε να συγκεντρωθήτε στις ερωτήσεις κάντε ένα διάλειμμα. Μπορείτε να συμπληρώσετε το ερωτηματολόγιο μέσα σε μια με δύο μέρες.**
- **Μερικές ερωτήσεις έχουν έναν αστερίσκο (*) στην αρχή τους, ο οποίος ενδεικνύει ότι η απάντηση είναι απαραίτητη. Παρακαλώ, απαντήστε σε αυτές τις ερωτήσεις εάν είναι εφαρμόσιμες σ' εσάς.**
- **Με βάση τις απαντήσεις σας μπορεί να παρακάμψετε κάποιες ερωτήσεις. Παρακαλώ, ακολουθήστε τις οδηγίες των ερωτήσεων.**

Σας ευχαριστούμε πολύ

Συντομογραφίες: Κάκωση Νωτιαίου Μυελού (ΚΝΜ), Οπτική Αναλογική κλίμακα (ΟΑΚ), *απαντήστε στην ερώτηση εάν σας αφορά

ΕΡΩΤΗΜΑΤΟΛΟΓΙΟ ΑΞΙΟΛΟΓΗΣΗΣ ΠΟΝΟΥ

*Η παρακάτω φωτογραφία είναι το διάγραμμα σωματικού πόνου το οποίο θα σας βοηθήσει να προσδιορίσετε τις περιοχές στις οποίες νοιώθετε πόνο



Παρακαλώ, σημειώστε στο παραπάνω σχεδιάγραμμα που στο σώμα σας αισθάνεστε πόνο. Τοποθετήστε **Ε** αν ο πόνος είναι εξωτερικός, ή **Μ** αν είναι εσωτερικός, ή **ΕΜ** αν εξωτερικός και εσωτερικός πόνος υπάρχει στις περιοχές που σημειώνετε.

Συντομογραφίες: Κάκωση Νωτιαίου Μυελού (ΚΝΜ), Οπτική Αναλογική Κλίμακα (ΟΑΚ), Δείκτης Διαβάθμισης Πόνου (ΔΔΠ), Ένταση Παρόντος Πόνου (ΕΠΠ), *απαντήστε στην ερώτηση εάν σας αφορά

1) *Από τότε που αποκτήσατε την ΚΝΜ σας έχετε νοιώσει πόνο στην μέση (οσφυαλγία)

Ναι ❑ (παρακαλώ, συνεχίστε στην παρακάτω ερώτηση)

Όχι ❑ (παρακαλώ, πάτε στο EQ-5D, σελίδα 5)

I. **Δείκτης Διαβάθμισης Πόνου (ΔΔΠ)**

Οι παρακάτω λέξεις περιγράφουν τον **κατά μέσο όρο** πόνο. Βάλτε ένα σημάδι (√) στην στήλη η οποία αντιπροσωπεύει τον βαθμό στον οποίο αισθάνεστε τον τύπο αυτό πόνου. Παρακαλώ, περιοριστείτε στην περιγραφή του πόνου στην περιοχή της **μέση σας** μόνο (οσφυϊκός πόνος).

	Καθόλου πόνος	Ήπιος	Μέτριος	Έντονος
Παλμικός-ρυθμικός				
Σαν να 'περπατάει'				
Σαν ΄μαχαιριά'				
Οξύς				
Σαν 'κραμπα'				
Σαν να 'δαγκώνει'				
Καυστικός-ζεστός				
Γενικός-διαρκής				
Αίσθημα βάρους				
Ευαίσθητος				
Διαμελιστικός-σαν να σε 'σκίζει'				
Κουραστικός				
Αηδιαστικός-νοσηρός				
Τρομακτικός				
Βασανιστικός-σκληρός				

II. ***Ένταση Παρόντος Πόνου (ΕΠΠ)** – Οπτική Αναλογική Κλίμακα (ΟΑΚ). Βάλτε ένα σημάδι "**x**" κατά μήκος της γραμμής για να υποδείξετε τον πόνο που νοιώθετε τώρα στην **μέση σας** (οσφυϊκός πόνος).

Καθόλου πόνος |_____| **Ο χειρότερος πόνος που έχε νοιώσει ποτέ**

Συντομογραφίες: Κάκωση Νωτιαίου Μυελού (ΚΝΜ), Οπτική Αναλογική Κλίμακα (ΟΑΚ), Δείκτης Διαβάθμισης Πόνου (ΔΔΠ), Ένταση Παρόντος Πόνου (ΕΠΠ), *απαντήστε στην ερώτηση εάν σας αφορά

- ***Ένταση Συνήθη Πόνου – τελευταίους 3 μήνες.**

Βάλτε ένα σημάδι "**x**" κατά μήκος της γραμμής για να υποδείξετε τον πόνο που **συνήθως** νοιώθετε στην **μέση σας** (οσφυϊκός πόνος) τους τελευταίους **3** μήνες.

Καθόλου πόνος |_____| **Ο χειρότερος πόνος που έχε νοιώσει ποτέ**

- ***Ένταση Συνήθη Πόνου – τελευταίος μήνας.**

Βάλτε ένα σημάδι "**x**" κατά μήκος της γραμμής για να υποδείξετε τον πόνο που **συνήθως** νοιώθετε στην **μέση σας** (οσφυϊκός πόνος) τον τελευταίο **1** μήνα.

Καθόλου πόνος |_____| **Ο χειρότερος πόνος που έχε νοιώσει ποτέ**

III. ***Εκτιμόμενη συνολική ένταση ολικής εμπειρίας του πόνου.**

Παρακαλώ, περιοριστείτε στην περιγραφή του πόνου στην περιοχή της **μέση σας** μόνο (οσφυϊκός πόνος). Βάλτε ένα σημάδι (√) στην κατάλληλη στήλη.

Εκτίμηση	
Καθόλου πόνος	
Ήπιος	
Ενοχλητικός	
Οδυνηρός	
Φρικτός	
Αφόρητος	

EQ - 5D

Ερωτηματολόγιο για την Υγεία

Βάζοντας ένα ✓ σε ένα κουτάκι κάθε ομάδας παρακάτω, παρακαλούμε σημειώστε ποιές δηλώσεις περιγράφουν καλύτερα την κατάσταση της υγείας σας **σήμερα**.

Κινητικότητα

Δεν έχω κανένα πρόβλημα στο περπάτημα ❑
Έχω μερικά προβλήματα στο περπάτημα ❑
Είμαι καθηλωμένος/η στο κρεβάτι ❑

Αυτοεξυπηρέτηση

Δεν έχω κανένα πρόβλημα με την αυτοεξυπηρέτησή μου ❑
Έχω μερικά προβλήματα στο να πλένομαι και να ντύνομαι ❑
Είμαι ανίκανος/η να πλυθώ ή να ντυθώ ❑

Συνηθισμένες Δραστηριότητες (*π.χ. δουλειά, μελέτη, νοικοκυριό, οικογενειακές δραστηριότητες ή δραστηριότητες ελεύθερου χρόνου)*

Δεν έχω κανένα πρόβλημα στο να εκτελώ τις συνηθισμένες δραστηριότητές μου ❑
Έχω μερικά προβλήματα στο να εκτελώ τις συνηθισμένες δραστηριότητές μου ❑
Είμαι ανίκανος/η να εκτελώ τις συνηθισμένες δραστηριότητές μου ❑

Πόνος/Δυσφορία

Δεν έχω καθόλου πόνο ή δυσφορία ❑
Έχω μέτριο πόνο ή δυσφορία ❑
Έχω υπερβολικό πόνο ή δυσφορία ❑

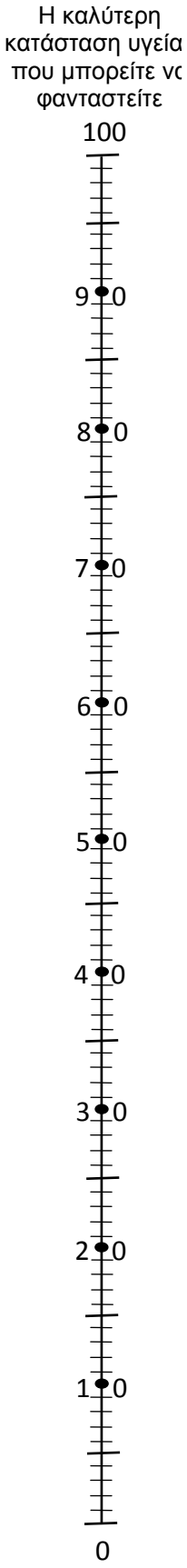
Άγχος /Θλίψη

Δεν έχω άγχος ή θλίψη ❑
Έχω μέτριο άγχος ή θλίψη ❑
Έχω υπερβολικό άγχος ή θλίψη ❑

*Για να βοηθήσουμε κάποιον να πει πόσο καλή ή κακή είναι μια κατάσταση υγείας, ζωγραφίσαμε μια κλίμακα (σαν ένα θερμόμετρο) πάνω στην οποία η καλύτερη κατάσταση που μπορείτε να φανταστείτε έχει βαθμό 100 και η χειρότερη κατάσταση που μπορείτε να φανταστείτε έχει βαθμό 0.

Θα θέλαμε να σημειώσετε πάνω σε αυτήν την κλίμακα πόσο καλή ή κακή είναι η υγεία σας **σήμερα**, κατά τη γνώμη σας. Παρακαλούμε κάντε το αυτό, τραβώντας μια γραμμή από το παρακάτω τετράγωνο προς οποιοδήποτε σημείο της κλίμακας δείχνει πόσο καλή ή κακή είναι η κατάσταση της υγείας σας σήμερα.

Η κατάσταση της δικής σας υγείας σήμερα



Συντομογραφίες: Τραχειακός σωλήνας (ΤΣ), Διαλείποντας υποβοηθούμενος αερισμός (ΔΥΑ), Υπολοιπόμενος όγκος ούρων (ΥΟΟ)

GR- SCIM III - Spinal Cord Independence Measure – Έκδοση III

Αυτοεξυπηρέτηση

3. Σίτιση (κόψιμο τροφής, άνοιγμα δοχείων, σερβίρισμα υγρού, μεταφορά τροφής στο στόμα, κράτημα φλυτζανιού με υγρό)

0. Χρειάζεται παρεντερική, γαστροστόμια ή πλήρως υποβοηθούμενη σίτηση από το στόμα
1. Χρειάζεται μερική βοήθεια για τη σίτιση και/ή την πόση ή για να φορέσει προσαροστικά βοηθήματα
2. Τρώω ανεξάρτητα. Χρειάζονται προσαρμοστικά βοηθήματα ή βοήθεια μόνο για το κόψιμο της τροφής και/ή το σερβίρισμα υγρού και/ή το άνοιγμα δοχείων
3. Τρώω και πίνω ανεξάρτητα. Δεν απαιτείται βοήθεια ή προσαρμοστικά βοηθήματα

4. **Μπάνιο** (σαπούνισμα, πλύσιμο, στέγνωμα σώματος και κεφαλής, χειρισμός βρύσης).

Α - Άνω μέρος σώματος

0. Απαιτείται πλήρης βοήθεια

6. Απαιτείται μερική βοήθεια
7. Πλένομαι ανεξάρτητα χρησιμοποιώντας προσαρμοστικά βοηθήματα ή σε ειδικά προσαρμοσμένο περιβάλλον (π.χ. μπάρες στήριξης, καρέκλα)
8. Πλένομαι ανεξάρτητα. Δεν απαιτείται χρήση προσαρμοστικών βοηθημάτων ή ειδικά προσαρμοσμένο περιβάλλον

Β - Κάτω μέρος σώματος

0. Απαιτείται πλήρης βοήθεια

1. Απαιτείται μερική βοήθεια
2. Πλένομαι ανεξάρτητα χρησιμοποιώντας προσαρμοστικά βοηθήματα ή σε ειδικά προσαρμοσμένο περιβάλλον
3. Πλένομαι ανεξάρτητα. Δεν απαιτείται χρήση προσαρμοστικών βοηθημάτων ή ειδικά προσαρμοσμένο περιβάλλον

5. **Ντύσιμο** (ρούχα, παπούτσια, μόνιμες ορθώσεις, ντύσιμο, γδύσιμο).

Α - Άνω μέρος σώματος

0. Απαιτείται πλήρης βοήθεια

5. Απαιτείται μερική βοήθεια με ρούχα χωρίς κουμπιά, φερμουάρ ή κορδόνια
6. Ανεξάρτητος/-η με ρούχα χωρίς κουμπιά, φερμουάρ ή κορδόνια. Απαιτείται χρήση προσαρμοστικών βοηθημάτων ή ειδικά προσαρμοσμένο περιβάλλον
7. Ανεξάρτητος/-η με ρούχα χωρίς κουμπιά, φερμουάρ ή κορδόνια. Δεν απαιτούνται προσαρμοστικά βοηθημάτα ή ειδικά προσαρμοσμένο περιβάλλον. Χρειάζεται βοήθεια ή προσαρμοστικά βοηθημάτα ή ειδικά
8. προσαρμοσμένο περιβάλλον μόνο για κουμπιά, φερμουάρ ή κορδόνια
9. Ντύνομαι ανεξάρτητα (όλα τα ρούχα). Δεν απαιτούνται προσαρμοστικά βοηθήματα ή ειδικά προσαρμοσμένο περιβάλλον

Β - Κάτω μέρος σώματος

0. Απαιτείται πλήρης βοήθεια

1. Απαιτείται μερική βοήθεια με ρούχα χωρίς κουμπιά, φερμουάρ ή κορδόνια
2. Ανεξάρτητος/-η με ρούχα χωρίς κουμπιά, φερμουάρ ή κορδόνια. Απαιτείται χρήση προσαρμοστικών βοηθημάτων ή ειδικά προσαρμοσμένο περιβάλλον
3. Ανεξάρτητος/-η με ρούχα χωρίς κουμπιά, φερμουάρ ή κορδόνια. Δεν απαιτούνται προσαρμοστικά βοηθημάτα ή ειδικά προσαρμοσμένο περιβάλλον. Χρειάζεται βοήθεια ή προσαρμοστικά βοηθημάτα ή ειδικά προσαρμοσμένο περιβάλλον μόνο για κουμπιά, φερμουάρ ή κορδόνια
4. Ντύνομαι ανεξάρτητα (όλα τα ρούχα). Δεν απαιτούνται προσαρμοστικά βοηθήματα ή ειδικά προσαρμοσμένο περιβάλλον

4. Περιποίηση (Πλύσιμο χεριών και προσώπου, βούρτσισμα δοντιών, χτένισμα μαλλιών, ξύρισμα, μακιγιάρισμα)

0. Απαιτείται πλήρης βοήθεια
1. Απαιτείται μερική βοήθεια
2. Ανεξάρτητη περιποίηση χρησιμοποιώντας προσαρμοστικά βοηθήματα
3. Ανεξάρτητη περιποίηση χωρίς προσαρμοστικά βοηθήματα

Αναπνοή και διαχείρηση σφιγκτήρα

1. Αναπνοή

1. Απαιτείται τραχειακός σωλήνας (ΤΣ) και μόνιμος ή διαλείποντας υποβοηθούμενος αερισμός (ΔΥΑ)
2. Ανεξάρτητη αναπνοή με ΤΣ. Απαιτείται οξυγόνο, πολλή βοήθεια στο βήξιμο ή στην διαχείρηση του ΤΣ
4. Ανεξάρτητη αναπνοή με ΤΣ. Απαιτείται λίγη βοήθεια στο βήξιμο ή στη διαχείριση του ΤΣ
6. Ανεξάρτητη αναπνοή χωρίς ΤΣ. Απαιτείται οξυγόνο, πολλή βοήθεια στο βήξιμο ή στην διαχείρηση του ΤΣ
8. Αναπνοή χωρίς ΤΣ. Απαιτείται λίγη βοήθεια ή διέγερση για βήξιμο
10. Ανεξάρτητη αναπνοή χωρίς βοήθεια ή βοηθήματα

6. Διαχείρηση σφιγκτήρα – Ουροδόχος κύστη

0. Εμφυτευμένος καθετήρας
3. Υπολοιπόμενος όγκος ούρων (ΥΟΟ) > 100 κυβικά εκατοστά. Κανένας τακτικός καθετηριασμός ή υποβοηθούμενος διαλείποντας καθετηριασμός
6. ΥΟΟ < 100 κυβικά εκατοστά ή διαλείπων αυτοκαθετηριασμός. Χρειάζομαι βοήθεια για την εφαρμογή συσκευής παροχέτευσης
9. Διαλείποντας αυτοκαθετηριασμός. Χρήση εξωτερικής συσκευής παροχέτευσης. Δεν χρειάζομαι βοήθεια για την εφαρμογή
11. Διαλείποντας αυτοκαθετηριασμός. Εγκράτεια μεταξύ καθετηριασμών. Δεν χρησιμοποιείται εξωτερική συσκευή παροχέτευσης
13. ΥΟΟ < 100 κυβικά εκατοστά. Χρειάζεται μόνο εξωτερική ουρική παροχέτευση. Δεν απαιτείται βοήθεια για παροχέτευση
15. Υ.Ο.Ο <100 κυβικά εκατοστά. Δεν χρησιμοποιείται εξωτερική συσκευή παροχέτευσης

7. Διαχείριση σφιγκτήρα - Έντερο

0. Αφόδευση με ακανόνιστο χρονισμό ή πολύ μικρής συχνότητας (λιγότερο απο μία φορά σε 3 ημέρες)
5. Κανονικός χρονισμός, αλλά απαιτείται βοήθεια (π.χ. για τοποθέτηση υποθέτου). Σπάνια ατυχήματα (λιγότερο από μια φορά το μήνα)
8. Κανονική αφόδευση, χωρίς βοήθεια. Σπάνια ατυχήματα (λιγότερο από μια φορά το μήνα)
10. Κανονική αφόδευση, χωρίς βοήθεια, χωρίς ατυχήματα

8. Χρήση τουαλέτας (Υγιεινή περίνεου, τακτοποίηση ρούχων πριν/μετά, χρήση πάνας)

3. Απαιτείται πλήρης βοήθεια
4. Απαιτείται μερική βοήθεια. Δεν καθαρίζομαιι μόνος/-η
5. Απαιτείται μερική βοήθεια. Καθαρίζομαι μόνος/-η
4. Ανεξάρτητος/-η σε όλες τις δραστηριότητες τουαλέτας αλλά χρειάζονται προσαρμοστικά βοηθήματα ή ειδικά προσαρμοσμένο περιβάλλον (π.χ. μπάρες)
5. Ανεξάρτητος/-η στην τουαλέτα. Δεν απαιτούνται προσαρμοστικά βοηθήματα ή ειδικά προσαρμοσμένο περιβάλλον

Κινητικότητα (δωμάτιο και τουαλέτα)

9. Κινητικότητα στο κρεβάτι και μέτρα για την αποφυγή κατακλίσεων

0. Χρειάζομαι βοήθεια σε όλες τις δραστηριότητες. Γυρίζω το άνω μέρος του σώματος στο κρεβάτι, γυρίζω το κάτω μέρος του σώματος στο κρεβάτι, ανακάθομαι στο κρεβάτι. Κάνω ανασήκωμα στο αναπηρικό αμαξίδιο, με ή χωρίς προσαρμοστικά βοηθήματα αλλά όχι με ηλεκτρικά βοηθήματα
2. Εκτελώ μία από τις δραστηριότητες χωρίς βοήθεια
4. Εκτελώ δύο ή τρεις από τις δραστηριότητες χωρίς βοήθεια
6. Εκτελώ ανεξάρτητα όλες τις δραστηριότητες στο κρεβάτι και όλες τις δραστηριότητες απελευθέρωσης πίεσης

10. Μεταφορές: κρεβάτι - αναπηρικό αμαξίδιο (κλείδωμα αμαξιδίου, ανασήκωση υποποδίων, αφαίρεση και προσαρμογή του βραχίονα, μεταφορά, ανασήκωμα ποδιών)

3. Απαιτείται πλήρης βοήθεια
4. Χρειάζεται μερική βοήθεια και/ή επίβλεψη, και/ή προσαρμοστικά βοηθήματα (π.χ. σανίδα μεταφοράς)
5. Ανεξάρτητος/-η (ή δεν απαιτείται αναπηρικό αμαξίδιο)

Συντομογραφίες: Κάκωση Νωτιαίου Μυελού (ΚΝΜ), Εθνικό Σύστημα Υγείας (ΕΣΥ), Διαδερμική Ηλεκτρική Διέγερση Νεύρων (ΤΕΝΣ), *απαντήστε στην ερώτηση εάν σας αφορά

11. Μεταφορές: αναπηρικό αμαξίδιο - τουαλέτα - νιπτήρας (εάν χρησιμοποιείται αναπηρικό αμαξίδιο τουαλέτας): μεταφορές προς και από; εάν χρησιμοποιείται κανονικό αναπηρικό αμαξίδιο: κλείδωμα αμαξιδίου, ανασήκωση υποποδίων, αφαίρεση και προσαρμογή του βραχίονα, μεταφορά, ανασήκωμα ποδιών)

0. Απαιτείται πλήρης βοήθεια
1. Χρειάζεται μερική βοήθεια και/ή επίβλεψη, και/ή προσαρμοστικά βοηθήματα (π.χ. μπάρες στήριξης)
2. Ανεξάρτητος/-η (ή δεν απαιτείται αναπηρικό αμαξίδιο)

Κινητικότητα (σε εσωτερικούς και εξωτερικούς χώρους, ή επίπεδη επιφάνεια)

12. Κινητικότητα σε εσωτερικούς χώρους

9. Απαιτείται πλήρης βοήθεια
10. Χρειάζεται ηλεκτρικό αναπηρικό αμαξίδιο ή μερική βοήθεια για το χειρισμό χειροκίνητου αναπηρικού αμαξιδίου
11. Ανεξάρτητη κινητικότητα με χειροκίνητο αναπηρικό αμαξιδίο
12. Απαιτείται επίβλεψη κατά τη βάδιση (με ή χωρίς βοηθήματα)
13. Βάδιση με πλαισίο βάδισης “Π” ή πατερίτσες (αιώρηση)
14. Βάδιση με πατερίτσες ή δύο μπαστούνια (αμφοτερόπλευρη βάδιση)
15. Βάδιση με ένα μπαστούνι
16. Χρειάζεται μηροκνημοποδικός κηδεμόνας
17. Βάδιση χωρίς βοηθήματα

13. Κινητικότητα για μέτριες αποστάσεις (10-100 μέτρα)

0. Απαιτείται πλήρης βοήθεια
1. Χρειάζεται ηλεκτρικό αναπηρικό αμαξίδιο ή μερική βοήθεια για το χειρισμό χειροκίνητου αναπηρικού αμαξιδίου
2. Ανεξάρτητη κινητικότητα με χειροκίνητο αναπηρικό αμαξιδίο
3. Απαιτείται επίβλεψη κατά τη βάδιση (με ή χωρίς βοηθήματα)
4. Βάδιση με πλαισίο βάδισης “Π” ή πατερίτσες (αιώρηση)
5. Βάδιση με πατερίτσες ή δύο μπαστούνια (αμφοτερόπλευρη βάδιση)
6. Βάδιση με ένα μπαστούνι
7. Χρειάζεται μηροκνημοποδικός κηδεμόνας
8. Βάδιση χωρίς βοηθήματα

14. Κινητικότητα σε εξωτερικό χώρο (άνω των 100 μέτρων)

0. Απαιτείται πλήρης βοήθεια
1. Χρειάζεται ηλεκτρικό αναπηρικό αμαξίδιο ή μερική βοήθεια για το χειρισμό χειροκίνητου αναπηρικού αμαξιδίου
2. Ανεξάρτητη κινητικότητα με χειροκίνητο αναπηρικό αμαξιδίο
3. Απαιτείται επίβλεψη κατά τη βάδιση (με ή χωρίς βοηθήματα)
4. Βάδιση με πλαισίο βάδισης “Π” ή πατερίτσες (αιώρηση)
5. Βάδιση με πατερίτσες ή δύο μπαστούνια (αμφοτερόπλευρη βάδιση)
6. Βάδιση με ένα μπαστούνι
7. Χρειάζεται μηροκνημοποδικός κηδεμόνας
8. Βάδιση χωρίς βοηθήματα

15. Κινητικότητα σε σκάλα

4. Στερούμαι ικανότητας για ανέβασμα ή κατέβασμα σκάλας
5. Ανεβαίνω και κατεβαίνω τουλάχιστον 3 σκαλοπάτια με στήριξη ή επίβλεψη άλλου ατόμου

6. Ανεβαίνω και κατεβαίνω τουλάχιστον 3 σκαλοπάτια με στήριξη στο κάγκελο της σκάλας και/ή πατερίτσα ή μπαστούνι.
7. Ανεβαίνω και κατεβαίνω τουλάχιστον 3 σκαλοπάτια χωρίς στήριξη ή επίβλεψη

16. Μεταφορές: Αναπηρικό αμαξίδιο – αυτοκίνητο (προσέγγιση αυτοκινήτου, κλείδωμα αμαξιδίου, αφαίρεση βραχιόνων και υποποδίων, μεταφορά πρός και από το αυτοκίνητο, μεταφορά αμαξιδίου μέσα και έξω από το αυτοκίνητο)

0. Απαιτείται πλήρης βοήθεια
1. Χρειάζεται μερική βοήθεια και/ή επίβλεψη και/ή προσαρμοστικά βοηθήματα
2. Ανεξάρτητη μεταφορά. Δεν απαιτούνται προσαμοστικά βοηθήματα (ή δεν απαιτείται αναπηρικό αμαξίδιο)

17. Μεταφορές: έδαφος - αναπηρικό αμαξίδιο

0. Απαιτείται βοήθεια
1. Ανεξάρτητη μεταφορά με ή χωρίς προσαρμοστικά βοηθήματα (ή δεν απαιτείται αναπηρικό αμαξιδίο)

Κοινωνικο-δημογραφικές Πληροφορίες

Αυτό είναι το **τελευταίο μέρος** του ερωτηματολογίου. Αυτό το μέρος περιέχει τρεις ενότητες, η πρώτη ενότητα περιέχει ερωτήσεις για τον **εαυτό σας**, στην αρχή και στο τέλος του ερωτηματολογίου, η δεύτερη για τον **πόνο σας γενικότερα** και η τρίτη για την **οσφυαλγία σας**. Παρακαλώ, απαντήσετε στις ερωτήσεις με όσο το δυνατόν μεγαλύτερη ακρίβεια.

Ερωτήσεις για τον εαυτό σας

1) Ποιό είναι το φύλο σας;

Άνδρας ❑ Γυναίκα ❑

2) Ποιά είναι η ημερομηνία γέννησής σας _____/_____/_____

ημέρα μήνας έτος

3) Ποια είναι η μητρική σας γλώσσα;

Αγγλικά ❑ Γαλλικά ❑ Ισπανικά ❑ Αραβικά ❑ Ελληνικά ❑

Άλλη (παρακαλώ δηλώστε)_____

4) Ποια είναι η εθνικότητα σας;

Λευκή

Ελληνική ❑
Ανατολική Ευρωπαϊκή – μη Ελληνική ❑
Μεσογειακή – μη Ελληνική ❑
Ηνωμένο Βασίλειο (ΗΒ) ❑
Δυτική Ευρωπαϊκή – μη ΗΒ ❑
Βόρεια Ευρωπαϊκή ❑
Άλλη Λευκή ❑

Ασιατική

Τουρκική ❑
Πακιστανική ❑
Ινδική ❑
Κινεζική ❑
Ιαπωνική ❑
Άλλη Ασιατική ❑

Μικτή

Λευκή και Μαύρη Καραϊβική ❑
Λευκή και Μαύρη Αφρικανική ❑
Λευκή και Ασιατική ❑

Μαύρη

Καραϊβική ❑
Αφρικανική ❑
Άλλη Μαύρη ❑
Άλλη μικτή ❑

Εάν είπατε "*άλλη*" σε κάποιο από τα παραπάνω, παρακαλώ δηλώστε
_____
_____

5) Ποιο είναι το ανώτερο δίπλωμα/πτυχίο που έχετε αποκτήσει;

Λύκειο ❑
Κολλέγιο ή αντίστοιχο ❑
Πανεπιστήμιο ❑
Μεταπτυχιακό (μαστερ) ❑
Διδακτορικό ή αντίστοιχο ❑
Δεν έχω αποκτήσει κανένα δίπλωμα/πτυχίο ❑
Άλλο (παρακαλώ δηλώστε)_____

6) Ποια είναι η οικογενειακή σας κατάσταση;

Ελεύθερος ❑
Συζώ με σύντροφο ❑
Παντρεμένος ❑
Χήρος/α ❑
Σε διάσταση/ Διαζευμένος/η ❑
Σε σχέση ❑
Άλλο (παρακαλώ δηλώστε)_____

7) *Ποιο από τα παρακάτω περιγράφει καλύτερα την κύρια δραστηριότητά σας;

Ελεύθερος/-η επαγγελματίας ❑
Υπάλληλος ❑
Εθελοντική εργασία ❑
Εργάζομαι από το σπίτι ❑
Λαμβάνω επιδόματα υγείας ❑
Άνεργος/-η αλλά εργαζόμουν πριν από τη ΚΝΜ μου ❑
Δεν εργάζομαι χωρίς πότε να είχα έμμισθη εργασία ❑
Μη ικανός/-ή να εργαστώ λόγω της ΚΝΜ μου ❑
Σε αναζήτηση εργασίας ❑
Οικιακά ❑
Συνταξιούχος ❑
Φοιτητής/-τρια, μαθητής/-τρια ❑

Άλλο ❑ (παρακαλώ δηλώστε)_____

8) Ποιος είναι ο τόπος διαμονής σας;

Πόλη ή χωριό_____ Επαρχία_____

9) Ποια είναι η χιλιομετρική απόσταση μεταξύ της κατοικίας σας και του πλησιέστερου από τα ακόλουθα. Αν δε γνωρίζετε, παρακαλώ, αφήστε κενό.

Νοσοκομείο_____Χμ
Κέντρο Αποκατάστασης ΚΝΜ_____Χμ
Εξειδικευμένα Εξωτερικά Ιατρεία ΚΝΜ _____Χμ
Μονάδα Φυσιοθεραπείας ΕΣΥ_____Χμ
Ιδιωτικό Φυσικοθεραπευτήριο_____Χμ
Κέντρο Θεραπευτικής Ιππασίας_____Χμ

10) *Πότε αποκτήσατε την ΚΝΜ σας;

_____/_____/_____

ημέρα μήνας έτος

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11) *Ποια ήταν η ατία για την ΚΝΜ σας;

Τραυματική ❑ (παρακαλώ συνεχίστε με τις παρακάτω ερωτήσεις)
Μη-τραυματική ❑ (παρακαλώ, πηγαίνετε στην ερώτηση 13, σελίδα 15)

12) *Η αιτία της τραυματικής ΚΝΜ μου ήταν

Τροχαίο Ατύχημα
Ατύχημα με Αυτοκίνητο ❑
Ατύχημα με Μοτοσυκλέτα ❑
Ατύχημα ως πεζός ❑
Ατύχημα με Ποδήλατο ❑
Άλλη ❑

Ατύχημα λόγω άσκησης βίας
Βίαιη επίθεση ❑
Επίθεση με μαχαίρι ❑
Πυροβολισμός ❑
Άλλη ❑

Εργατικό ατύχημα
Ολισθηρό έδαφος ❑
Πτώση από σκάλα/σκαλιά ❑
Πτώση από σκαλωσιά ❑
Χάσιμο ισορροπίας από αντικείμενο στο έδαφος ❑
Άλλη ❑

Ατύχημα σε οικία
Ολισθηρό έδαφος ❑
Πτώση από σκαλιά ❑
Πτώση από παράθυρο ❑
Χάσιμο ισορροπίας από αντικείμενο στο έδαφος ❑
Άλλη ❑

Ατύχημα λόγω αθλήματος
Αγώνες ταχύτητας με αυτοκίνητο ❑
Αγώνες ταχύτητας με μοτοσυκλέτα ❑
Ποδόσφαιρο ❑
Ράγκμπυ ❑
Άλλη ❑
Ορειβασία ❑
Ποδηλασία ❑
Ιππασία ❑
Καταδύσεις ❑
Κολύμβηση ❑

Εάν "*άλλη*", παρακαλώ δηλωστε_____

Συντομογραφίες: Κάκωση Νωτιαίου Μυελού (ΚΝΜ), Εθνικό Σύστημα Υγείας (ΕΣΥ), Διαδερμική Ηλεκτρική Διέγερση Νεύρων (ΤΕΝΣ), Σπονδυλική στήλη (ΣΣ), *απαντήστε στην ερώτηση εάν σας αφορά

13) ***Η αιτία της μη-τραυματικής ΚΝΜ μου ήταν**

Αγγειακή

Αρτηριοσκλήρωση που οδηγεί σε απώλεια ανεφοδιασμού αίματος ❑
Εμβολή ❑
Επισκληρίδιος αιμορραγία ❑
Σοβαρή υπόταση που οδηγεί σε απώλεια ανεφοδιασμού αίματος ❑
Άλλη ❑

Καρκινογενής (Νεοπλασία)

Καρκίνος μέσα και γύρω από τις δομές του νωτιαίου μυελού
π.χ. μηνιγγίωμα, γλοίωμα κτλ ❑
Μεταστατικός καρκίνος από άλλη περιοχή
π.χ. πνεύμονας, στήθος, προστάτης κτλ ❑
Άλλη ❑

Φλεγμονές και μολύνσεις

Εγκάρσια μυελίτιδα ❑
Επισκληρίδιο απόστημα ❑
Σαρκοείδωση ❑
Φυματίωση ❑
Άλλη ❑

Εκφυλιστική

Νόσος Paget των οστών ❑
Οστεοαρθρίτιδα ❑
Οστεοπόρωση ❑
Ρευματοειδής αρθρίτιδα ❑
Σπονδυλόλυση ❑
Άλλη ❑

Παραμόρφωση Σ.Σ.

Δισχιδής ράχη ❑
Κύφωση ❑
Κυφωλόρδωση ❑
Κυφωσκολίωση ❑
Λόρδωση ❑
Σκολίωση ❑
Άλλη ❑

Άλλη νευρολογική

Αταξία Friedreich's ❑
Εγκεφαλική παράλυση ❑
Σκλήρυνση κατα πλάκας ❑
Άλλη ❑

Εάν "*άλλη*", παρακαλώ δηλωστε_____

14) *Ποιο είναι το επίπεδο της κάκωσης σας; Παρακαλώ δηλώστε τον αριθμό του σπονδύλου.

Αυχενικοί είναι οι πρώτοι 7 σπόνδυλοι της Σ.Σ, γνωστοί ως Α1 έως Α7
Θωρακικοί (άνω πλάτη) είναι οι επόμενοι 12 σπόνδυλοι, γνωστοί ως Θ1 έως Θ12
Οσφυικοί (κατώτερη πλάτη) είναι οι επόμενοι 5 σπόνδυλοι, γνωστοί ως Ο1 έως Ο5

Το επίπεδο της κάκωσης μου είναι

Αυχενικός_____ Θωρακικός_____ Οσφυϊκός_____

15) *Ποιος είναι ο τύπος της ΚΝΜ σας;

Πλήρης παραπληγία ❑ Πλήρης τετραπληγία ❑
Μερική παραπληγία ❑ Μερική τετραπληγία ❑
Δεν γνωρίζω ❑
΄Αλλος ❑ (παρακαλώ δηλώστε)_____

16) Ποιο είναι το είδος της ασφάλειας υγείας που έχετε;

ΕΣΥ ❑ Ιδιωτική ❑ Και οι δύο ❑

Άλλο (παρακαλώ δηλώστε)_____

17) Ποιά απο τις παραπάνω ασφάλειες έχετε κυρίως χρησιμοποιήσει για τις διάφορες θεραπείες για την ΚΝΜ σας;

ΕΣΥ ❑ Και τις δυο ❑
Ιδιωτική ❑ Καμμία ❑
Άλλη ❑ (παρακαλώ δηλώστε)_____

18) Που λάβατε την πρώτη σας θεραπεία για την ΚΝΜ σας;

Νοσοκομείο του ΕΣΥ ❑ Ιδιωτικό κέντρο αποκατάστασης ❑
Ιδιωτικό Νοσοκομείο ❑ Δημόσιο κέντρο ΚΝΜ ❑
Δημόσιο κέντρο αποκατάστασης ❑ Ιδιωτικό κέντρο ΚΝΜ ❑
Άλλο (παρακαλώ δηλώστε)_____

19) Σε ποια χώρα λάβατε την πρώτη σας θεραπεία για την ΚΝΜ σας;

Ελλάδα ❑

Άλλη ❑ (παρακαλώ δηλώστε)_____

20) Πόσο καιρό παραμείνατε στο παραπάνω νοσοκομείο/κέντρο μετά από την ΚΝΜ σας;

Αν στη συνέχεια μεταφερθήκατε σε άλλη μονάδα (π.χ. κέντρο ΚΝΜ) παρακαλώ αναφέρετε πόσο καιρό επιπλέον μείνατε εκεί.
(Παρακαλώ, δηλώστε αν μήνες ή εβδομάδες)

Αρχικό νοσοκομείο/κέντρο για_____

Μεταφέρθηκα σε άλλη μονάδα για_____

21) Έχετε υποβληθεί σε χειρουργική επέμβαση μετά τη ΚΝΜ σας;

Όχι ❑

Ναι ❑ (παρακαλώ δηλώστε σε τι χειρουργικής επέμβασης υποβληθήκατε)

Υποβλήθηκα σε_____

_____

_____

22) Οι φίλοι και η οικογένειά σας σάς υποστηρίζουν στην ΚΝΜ σας;

Ναι	❑	Δεν θέλω την υποστήριξή τους	❑
Όχι	❑	Δεν χρειάζομαι την υποστήριξή τους	❑
Όχι όση χρειάζομαι	❑	Δεν θέλω να αναφέρω	❑

Άλλο (παρακαλώ δηλώστε)_____

Ερωτήσεις για τον πόνο σας γενικότερα

23) *Από τότε που αποκτήσατε την ΚΝΜ σας έχετε νοιώσει πόνο;

Ναι ❑ (παρακαλώ, συνεχίστε με τις παρακάτω ερωτήσεις)

Όχι ❑ (παρακαλώ πηγαίνετε στην ερώτηση 34, σελίδα 20)

24) *Πόσο καιρό μετά από την ΚΝΜ σας ξεκίνησε ο πόνος;

Αμέσως μετά από την ΚΝΜ	❑	Μεταξύ 2 εβδομάδων και ενός μήνα	❑
Την επόμενη ημέρα	❑	Μεταξύ 1 - 3 μηνών	❑
Μετά από 3 ημέρες	❑	Μεταξύ 3 - 6 μηνών	❑
Μετά από 1 εβδομάδα	❑	Μεταξύ 6 μήνες και 1 χρόνου	❑
Μετά από 2 εβδομάδες	❑	Μετά από 1 χρόνο	❑

Άλλο (παρακαλώ δηλώστε)_____

25) *Κατά μέσο όρο τους τελευταίους 6 μήνες πόσες ημέρες το μήνα νοιώθετε πόνο;

1 - 4 ημέρες	❑	21 - 25 ημέρες	❑
5 - 9 ημέρες	❑	26 - 30 ημέρες	❑
10 -15 ημέρες	❑	Κάθε μέρα	❑
16 - 20 ημέρες	❑		

Αν ξεκινήσετε να πονάτε σε διάστημα μικρότερο από 6 μήνες, παρακαλώ δηλώσετε πόσο καιρό πρίν

26) *Από τι είδος πόνου υποφέρετε; Παρακαλώ, σημειώστε όλα όσα σχετίζονται.

Νευροπαθητικό πάνω από το επίπεδο της κάκωσης ❑
Νευροπαθητικό κάτω από το επίπεδο της κάκωσης ❑
Νευροπαθητικό στο επίπεδο της κάκωσης ❑
Άνω Άκρα ❑
Μυοσκελετικό ❑
Πόνο στην πλάτη ❑
Δεν γνωρίζω ❑
Άλλο ❑ (παρακαλώ δηλώστε)_____

27) *Λαμβάνετε φαρμακευτική αγωγή για τον πόνο σας;

Ναι ❑ (παρακαλώ, συνεχίστε με τις ερωτήσεις παρακάτω)

Όχι ❑ (παρακαλώ πηγαίνετε στην ερώτηση 30, σελίδα 18)

28) Πόσο συχνά λαμβάνετε φαρμακευτική αγωγή για τον πόνο;

Καθημερινά ❑ Όποτε νοιώθω πόνο ❑

Σε τακτική βάση ❑

Άλλο ❑ (παρακαλώ δηλώστε)_____

29) Όταν λαμβάνετε φαρμακευτική αγωγή για τον πόνο, πόσες ώρες περνάνε συνήθως για να επιστρέψει ο πόνος;

1 ώρα ❑ 4 ώρες ❑
2 ώρες ❑ 5-12 ώρες ❑
3 ώρες ❑ Πάνω από 12 ώρες ❑
Η φαρμακευτική αγωγή για τον πόνο δε βοηθάει ❑

Συντομογραφίες: Κάκωση Νωτιαίου Μυελού (ΚΝΜ), Εθνικό Σύστημα Υγείας (ΕΣΥ), Διαδερμική Ηλεκτρική Διέγερση Νεύρων (ΤΕΝΣ), *απαντήστε στην ερώτηση εάν σας αφορά

30) ***Κατά την παραμονής σας στο νοσοκομείο/κέντρο** αξιολογηθήκατε από επαγγελματίες υγείας για τον πόνο σας; (Παρακαλώ, σημειώστε όλα όσα σχετίζονται)

Ναι, αξιολογήθηκα αμέσως από το γιατρό❑

Ναι, αξιολογήθηκα αμέσως από το νοσηλευτή/τρια❑

Ναι, αξιολογήθηκα αμέσως από το φυσικοθεραπευτή/τρια❑

Αξιολογήθηκα από το γιατρό, αλλά μόνο αφού παραπονέθηκα για πόνο❑

Αξιολογήθηκα από νοσηλευτή/τρια, αλλά μόνο αφού παραπονέθηκα για πόνο❑

Αξιολογήθηκα από φυσιοθεραπευτή/τρια, αλλά μόνο αφού παραπονέθηκα για πόν

Αξιολογήθηκα πολύ καιρό μετά την έναρξη του πόνος μου❑

Όχι, δεν αξιολογήθηκα από κανένα για τον πόνο μου❑

Άλλο ❑ (παρακαλώ δηλώστε)_____

31) ***Κατά την παραμονή σας στο νοσοκομείο/κέντρο**, τι είδος θεραπείας για τον **πόνο** λάβατε; Παρακαλώ, δηλώστε όλα όσα σχετίζονται.

Φαρμακευτική αγωγή πόνου	❑	Τεχνικές Χαλάρωσης	❑
Φυσικοθεραπεία	❑	Ηλεκτροθεραπεία	❑
Κρυοθεραπεία	❑	Βελονισμός	❑
Θερμοθεραπεία	❑	Κινησιοθεραπεία	❑
ΤΕΝΣ	❑	Ασκήσεις ενδυνάμωσης	❑

Δεν ένοιωθα κάποιο πόνο όσο ήμουν στο νοσοκομείο/κέντρο ❑

Ένοιωθα πόνο αλλά δε μου προσφέρθηκε καμία θεραπεία ❑

Δεν θυμάμαι ❑

Άλλο ❑ (παρακαλώ δηλώστε)_____

Συντομογραφίες: Κάκωση Νωτιαίου Μυελού (ΚΝΜ), Εθνικό Σύστημα Υγείας (ΕΣΥ), Διαδερμική Ηλεκτρική Διέγερση Νεύρων (ΤΕΝΣ), *απαντήστε στην ερώτηση εάν σας αφορά

32) **Κατά την παραμονή σας στο νοσοκομείο/κέντρο**, πόσο συχνά λαμβάνατε θεραπεία για τον πόνο;

Μη ισχύων ❑
Φαρμακευτική αγωγή πόνου_____
Φυσικοθεραπεία_____
Κρυοθεραπεία_____
Θερμοθεραπεία_____
ΤΕΝΣ_____
Τεχνικές χαλάρωσης_____
Ηλεκτροθεραπεία_____
Βελονισμός_____
Κινησιοθεραπεία_____
Μασάζ_____

*απαντήστε στην ερώτηση εάν σας αφορά

Ασκήσεις ενδυνάμωσεις_____
Άλλο (παρακαλώ δηλώστε) _____

33) ***Από τότε που φύγατε από το νοσοκομείο/κέντρο** έχετε λάβει θεραπεία για τον πόνο; Παρακαλώ, δηλώστε όλα τα είδη θεραπειών που είχατε.

Φαρμακευτική αγωγή πόνου ❑
Φυσικοθεραπεία ❑
Κρυοθεραπεία ❑
Θερμοθεραπεία ❑
ΤΕΝΣ ❑
Τεχνικές χαλάρωσης ❑
Ηλεκτροθεραπεία ❑
Βελονισμός ❑
Κινησιοθεραπεία ❑
Μασάζ ❑
Ασκήσεις ενδυνάμωσεις ❑
Θεραπευτική ιππασία ❑
Δεν ένοιωθα καθόλου πόνο ❑
Ένοιωθα πόνο αλλά δεν έλαβα καμία θεραπεία για τον πόνο ❑
Δεν θυμάμε ❑
Άλλο (παρακαλώ δηλώστε) ❑_____

34) Απο τότε που **φύγατε απο το νοσοκομείο/κέντρο,** πόσο συχνά λαμβάνετε θεραπεία για τον πόνο;

Μη ισχύων ❑
Φαρμακευτική αγωγή πόνου_____
Φυσικοθεραπεία_____
Κρυοθεραπεία_____
Θερμοθεραπεία_____
ΤΕΝΣ_____
Τεχνικές χαλάρωσης_____
Ηλεκτροθεραπεία_____
Βελονισμός_____
Κινησιοθεραπεία_____
Μασάζ_____
Ασκήσεις ενδυνάμωσεις_____
Θεραπευτική ιππασία_____
Άλλο (παρακαλώ δηλώστε) _____

35) ***Εάν είχατε θεραπεία για τον πόνο** ποια πιστεύετε ότι σας βοήθησε περισσότερο; Εάν είναι περισσότερες από μία, παρακαλώ δηλώστε τις με σειρά αποτελεσματικότητας.

Μη ισχύων ❑
Φαρμακευτική αγωγή πόνου_____
Φυσικοθεραπεία_____
Κρυοθεραπεία_____
Θερμοθεραπεία_____
ΤΕΝΣ_____
Τεχνικές χαλάρωσης_____
Ηλεκτροθεραπεία_____
Βελονισμός_____
Κινησιοθεραπεία_____
Μασάζ_____
Ασκήσεις ενδυνάμωσεις_____
Θεραπευτική ιππασία_____
Άλλο (παρακαλώ δηλώστε) _____

36) **Κατά μέσο όρο**, από τότε που φύγατε από το νοσοκομείο/κέντρο,πόσο καιρό ήσασταν σε **λίστα αναμονής** για να λάβετε θεραπεία για τον πόνο σας;

Η θεραπεία ξεκίνησε αμέσως	❑	4 μήνες	❑
1 – 2 εβδομάδες	❑	5 μήνες	❑
1 μήνα	❑	6 μήνες	❑
2 μήνες	❑	Πάνω από 6 μήνες	❑
3 μήνες	❑	Δεν ήμουν σε λίστα αναμονής	❑

Άλλο (παρακαλώ δηλώστε)_____

37) *Από τότε που πρωτοεμφανίστηκε ο πόνος σας, υπήρξε περίοδο **μίας εβδομάδας ή περισσότερο χωρίς πόνο;**

Ναι, τον περισσότερο καιρό	❑	Ναι, αλλά σπάνια	❑
Ναι, συχνά	❑	Όχι, πάντα ένοιωθα πόνο	❑
Ναι, μερικές φορές	❑	Δεν θυμάμαι	❑
Ναι, αλλά όχι πολύ συχνά	❑		

38) *Νοιώθετε **τώρα** κάποιο πόνο;

Όχι❑

Ναι ❑ (παρακαλώ, περιγράψτε τον με λίγα λόγια)

_____
_____
_____
_____
_____

Ερωτήσεις για την οσφυαλγία σας

39) Από τότε που αποκτήσατε την ΚΝΜ σας έχετε νοιώσει **οσφυαλγία**;

Ναι ❑ (παρακαλώ, συνεχίστε με τις παρακάτω ερωτήσεις)

Όχι ❑ (παρακαλώ, πηγαίνετε στην ερώτηση 53, σελίδα 25)

40) *Πόσο καιρό μετά από την ΚΝΜ σας ξεκίνησε η **οσφυαλγία** σας;

Αμέσως μετά από την ΚΝΜ	❑	Μεταξύ 2 εβδομάδων και ενός μήνα	❑
Την επόμενη ημέρα	❑	Μεταξύ 1 - 3 μηνών	❑
Μετά από 3 ημέρες	❑	Μεταξύ 3 - 6 μηνών	❑
Μετά από 1 εβδομάδα	❑	Μεταξύ 6 μήνες και 1 χρόνου	❑
Μετά από 2 εβδομάδες	❑	Μετά από 1 χρόνο	❑
Άλλο	❑ (παρακαλώ δηλώστε)_____		

41) *Κατά μέσο όρο τους τελευταίους 6 μήνες πόσες ημέρες το μήνα νοιώθετε οσφυαλγία;

1 - 4 ημέρες ❑	21 - 25 ημέρες ❑
5 - 9 ημέρες ❑	26 - 30 ημέρες ❑
10 -15 ημέρες ❑	Κάθε ημέρα ❑
16 - 20 ημέρες ❑	

Αν η οσφυαλγία πρωτοεμφανίστηκε πριν από διάστημα μικρότερο από 6 μήνες, παρακαλώ δηλώστε πρίν πόσο καιρό εμφανίστηκε.

_____

42) *Λαμβάνετε φαρμακευτική αγωγή για την **οσφυαλγία** σας;

Ναι ❑ (παρακαλώ, συνεχίστε με τις παρακάτω ερωτήσεις)
Όχι ❑ (παρακαλώ, πηγαίνετε στην ερώτηση 45, σελίδα 22)

43) *Πόσο συχνά λαμβάνετε φαρμακευτική αγωγή για την **οσφυαλγία**;

Καθημερινά	❑	Όποτε νοιώθω πόνο	❑
Σε τακτική βάση	❑		
Άλλο	❑ (παρακαλώ δηλώστε)_____		

44) Όταν λαμβάνετε φαρμακευτική αγωγή για την **οσφυαλγία**, πόσες ώρες περνάνε συνήθως για να επιστρέψει η οσφυαλγία;

1 ώρα	❑	4 ώρες	❑
2 ώρες	❑	5-12 ώρες	❑
3 ώρες	❑	Πάνω από 12 ώρες	❑
Η φαρμακευτική αγωγή για την οσφυαλγία δε βοηθάει			❑

45) ***Κατά την παραμονής σας στο νοσοκομείο/κέντρο** αξιολογηθήκατε από επαγγελματίες υγείας για την **οσφυαλγία** σας; (Παρακαλώ, σημειώστε όλα όσα σχετίζονται)

Ναι, αξιολογήθηκα αμέσως από το γιατρό❑
Ναι, αξιολογήθηκα αμέσως από το νοσηλευτή/τρια❑
Ναι, αξιολογήθηκα αμέσως από το φυσικοθεραπευτή/τρια❑
Αξιολογήθηκα από το γιατρό, αλλά μόνο αφού παραπονέθηκα για πόνο❑
Αξιολογήθηκα από νοσηλευτή/τρια, αλλά μόνο αφού παραπονέθηκα για πόνο❑
Αξιολογήθηκα από φυσιοθεραπευτή/τρια, αλλά μόνο αφού παραπονέθηκα για πόνο
Αξιολογήθηκα πολύ καιρό μετά την έναρξη του πόνος μου❑
Όχι, δεν αξιολογήθηκα από κανένα για τον πόνο μου❑
Άλλο ❑ (παρακαλώ δηλώστε)_____

46) ***Κατά την παραμονή σας στο νοσοκομείο/κέντρο**, τι είδος θεραπείας για την **οσφυαλγία** σας λάβατε; (Παρακαλώ, δηλώστε όλα όσα σχετίζονται)

Φαρμακευτική αγωγή πόνου	❑	Τεχνικές Χαλάρωσης	❑
Φυσικοθεραπεία	❑	Ηλεκτροθεραπεία	❑
Κρυοθεραπεία	❑	Βελονισμός	❑
Θερμοθεραπεία	❑	Κινησιοθεραπεία	❑
ΤΕΝΣ	❑	Ασκήσεις ενδυνάμωσης	❑
Δεν ένοιωθα κάποιο πόνο όσο ήμουν στο νοσοκομείο/κέντρο			❑
Ένοιωθα πόνο αλλά δε μου προσφέρθηκε καμία θεραπεία			❑
		Δεν θυμάμαι	❑
Άλλο	❑ (παρακαλώ δηλώστε)_____		

47) **Κατά την παραμονή σας στο νοσοκομείο/κέντρο**, πόσο συχνά λαμβάνατε θεραπεία για την **οσφυαλγία**;

Μη ισχύων ❑
Φαρμακευτική αγωγή πόνου_____
Φυσικοθεραπεία_____
Κρυοθεραπεία_____
Θερμοθεραπεία_____
ΤΕΝΣ_____
Τεχνικές χαλάρωσης_____
Ηλεκτροθεραπεία_____
Βελονισμός_____
Κινησιοθεραπεία_____
Μασάζ_____
Ασκήσεις ενδυνάμωσεις_____
Άλλο (παρακαλώ δηλώστε)_____

48) ***Από τότε που φύγατε από το νοσοκομείο/κέντρο**, τι είδος θεραπείας για την **οσφυαλγία** λαμβάνετε; Παρακαλώ, δηλώστε όλες τις θεραπείες που έχετε λάβει.

Φαρμακευτική αγωγή πόνου ❑
Φυσικοθεραπεία ❑
Κρυοθεραπεία ❑
Θερμοθεραπεία ❑
ΤΕΝΣ ❑
Τεχνικές χαλάρωσης ❑
Ηλεκτροθεραπεία ❑
Βελονισμός ❑
Κινησιοθεραπεία ❑
Μασάζ ❑
Ασκήσεις ενδυνάμωσεις ❑
Θεραπευτική ιππασία ❑
Δεν ένοιωθα καθόλου πόνο ❑
Ένοιωθα πόνο αλλά δεν έλαβα καμία θεραπεία για τον πόνο ❑
Δεν θυμάμε ❑
Άλλο (παρακαλώ δηλώστε) ❑_____

49) Απο τότε που **φύγατε απο το νοσοκομείο/κέντρο,** πόσο συχνά λαμβάνετε θεραπεία για την **οσφυαλγία σας**;

Μη ισχύων ❑
Φαρμακευτική αγωγή πόνου_____
Φυσικοθεραπεία_____
Κρυοθεραπεία_____
Θερμοθεραπεία_____
ΤΕΝΣ_____
Τεχνικές χαλάρωσης_____
Ηλεκτροθεραπεία_____
Βελονισμός_____
Κινησιοθεραπεία_____
Μασάζ_____
Ασκήσεις ενδυνάμωσεις_____
Θεραπευτική ιππασία_____
Άλλο (παρακαλώ δηλώστε) _____

50) ***Εάν είχατε θεραπεία για την οσφυαλγία** ποια πιστεύετε ότι σας βοήθησε περισσότερο; Εάν είναι περισσότερες από μία, παρακαλώ δηλώστε τις με σειρά αποτελεσματικότητας.

Μη ισχύων ❑
Φαρμακευτική αγωγή πόνου_____
Φυσικοθεραπεία_____
Κρυοθεραπεία_____
Θερμοθεραπεία_____
ΤΕΝΣ_____
Τεχνικές χαλάρωσης_____
Ηλεκτροθεραπεία_____
Βελονισμός_____
Κινησιοθεραπεία_____
Μασάζ_____
Ασκήσεις ενδυνάμωσεις_____
Θεραπευτική ιππασία_____
Άλλο (παρακαλώ δηλώστε) _____

51) Κατά **μέσο όρο**, από τότε που φύγατε από το νοσοκομείο/κέντρο,πόσο καιρό ήσασταν σε **λίστα αναμονής** για να λάβετε θεραπεία για την **οσφυαλγία** σας;

Η θεραπεία ξεκίνησε αμέσως	❑	4 μήνες	❑
1 – 2 εβδομάδες	❑	5 μήνες	❑
1 μήνα	❑	6 μήνες	❑
2 μήνες	❑	Πάνω από 6 μήνες	❑
3 μήνες	❑	Δεν ήμουν σε λίστα αναμονής	❑

Άλλο (παρακαλώ δηλώστε)_____

52) *Από τότε που πρωτοεμφανίστηκε η οσφυαλγία σας, υπήρξε περίοδο **μίας εβδομάδας ή περισσότερο χωρίς οσφυαλγία;**

Ναι, τον περισσότερο καιρό	❑	Ναι, αλλά σπάνια	❑
Ναι, συχνά	❑	Όχι, πάντα ένοιωθα πόνο	❑
Ναι, μερικές φορές	❑	Δεν θυμάμαι	❑
Ναι, αλλά όχι πολύ συχνά	❑		

Τελικές ερωτήσεις για τον εαυτό σας

53) Έχετε κάποιο πρόβλημα όρασης;

Ναι ❑ Όχι ❑

Εαν "*ναι*" παρακαλώ δηλώστε τι είδους_____

54) Διαβάσατε μόνος/-η σας το δελτίο πληροφοριών και το ερωτηματολόγιο;

Ναι ❑ Όχι ❑

Εαν "*όχι*", ποιος/-α σας βοήθησε με την ανάγνωση;

Παρακαλώ δηλώστε_____

55) Έχετε κάποιο πρόβλημα με το γράψιμο;

Ναι ❑ Όχι ❑

Εάν "*ναι*", παρακαλώ δηλώστε τι είδους_____

56) Συμπληρώσατε το ερωτηματολόγιο μόνος/-η σας, χωρίς τη βοήθεια κάποιου άλλου;

Ναι ❑ (παρακαλώ, πηγαίνετε στην ερώτηση 58, σελίδα 26)

Όχι ❑ (παρακαλώ, συνεχίστε με την ερώτηση 57 παρακάτω)

57) *Εάν κάποιος/-α άλλος/-η σας βοήθησε με τη συμπλήρωση του ερωτηματολογίου, πως σας βοήθησε;

Απαντούσα όλες τις ερωτήσεις αλλά κάποιος/-α άλλος/-η τις συμπλήρωνε χειρόγραφα για μένα ❑

Απαντούσα όλες τις ερωτήσεις αλλά κάποιος/-α άλλος/-η συμπλήρωσε χειρόγραφα για μένα την οπτική αναλογική κλίμακα (ΟΑΚ) και το διάγραμμα σωματικού πόνου ❑

Απαντούσα όλες τις ερωτήσεις αλλά κάποιος/-α άλλος/-η συμπλήρωσε χειρόγραφα για μένα μόνο την οπτική αναλογική κλίμακα (ΟΑΚ) ❑

Απαντούσα όλες τις ερωτήσεις αλλά κάποιος/-α άλλος/-η συμπλήρωσε χειρόγραφα για μένα μόνο το διάγραμμα σωματικού πόνου ❑

Άλλο (παρακαλώ δηλώστε)_____

58) *Παρακαλώ, δηλώστε την ημερομηνία που συμπληρώσατε αυτό το ερωτηματολόγιο

___/___/200___

Σας ευχαριστούμε πολύ για το χρόνο που διαθέσατε για την συμπλήρωση αυτού του ερωτηματολόγιο

Δελτίο Επιστροφής (προαιρετικό)

Παρακαλώ, δώστε μας το όνομα και τη διεύθυνσή σας για να μπορέσουμε να αναγνωρίσουμε το ερωτηματολόγιο σας σε περίπτωση που μας το ζητήσετε, ή να επικοινωνήσουμε μαζί σας για μελλοντικες έρευνες εάν συμφωνείτε.

Ονοματεπώνυμο_____

Διεύθυνση_____

Ταχυδρομικός Κωδικός_____

Τηλέφωνα Επικοινωνίας_____

Ηλεκτρονική Διεύθυνση (εάν υπάρχει)_____

Στο μέλλον, θα θέλατε να επικοινωνήσουμε μαζί σας και να σας πληροφορήσουμε για τα προγράμματα ερευνών μας;

Ναι ❑ Όχι ❑

Σας ευχαριστούμε πολύ για το χρόνο που διαθέσατε για την συμπλήρωση αυτού του ερωτηματολόγιου

Appendix 4; changes at pilot and translations

Supplement to Chapter 4

4.1 Feedback and changes during translations and pilot stage

Table 4.1.1: List of major words or phrases from SCIM III, in Greek, that underwent review and changes during the translation process

Word in English	Options under consideration (in Greek) of the same word	Final chosen word in Greek
(cutting) food	(Κόψιμο) "τροφής"	(Κόψιμο) "τροφής"
(holding) cup	(Κράτημα) "ποτηριού"	(Κράτημα) "φλυτζανιού"
(Sphincter) management	"Διαχείρηση" or "έλεγχος" (σφυκτήρων)	"διαχείρηση σφιγκτήρα"
; (symbol of semicolon)	":" or "." (because in Greek the symbol of semicolon is used the symbol of the question mark	
adjustment of clothes	"προσαρμογή" or "Τακτοποίηση" (ρούχων)	"τακτοποίηση ρούχων"
applying drainage instrument	"εφαρμογή παροχετευτικής συσκευής"	"εφαρμογή συσκευής παροχέτευσης"
arm rest	"μπράτσο" or "Βραχίονας"	"Βραχίονας"
bathing	"Πλύσιμο" or "Λούσιμο"	"Μπάνιο"
devices	"βοηθημάτα " or "συσκευές"	"Βοηθήματα"
Dressing	"Ντύσιμο" or "ένδυση"	"Ντύσιμο"
external drainage instrument	"εξωτερική παροχετευτική συσκευή"	"εξωτερική συσκευή παροχέτευσης"
fully assisted oral feeding	"στοματική σίτιση με πλήρη βοήθεια"	"πλήρως υποβοηθούμενη σίτηση από το στόμα"
grooming	"Ατομική Περιποίηση"	"Περιποίηση"
handrail	"Κουπαστή" or "κιγκλίδωμα" or "χερούλι σκάλας" or "κάγκελο σκάλας"	"κάγκελο της σκάλας"
intermittent	"διαλείπων" or "Περιοδικός"	"Διαλείποντας"
leg orthosis	"Κηδεμόνας" or "ορθωτήρας ποδιού"	"μηροκνημοποδικός κηδεμόνας"
push-ups (in wheelchair)	"Ανακάθισμα" (στο αναπηρικό αμαξίδιο)	"Ανασήκωμα" (στο αναπηρικό αμαξίδιο)
specific setting	"ειδικά (προσαρμοσμένο) περιβάλλον" or "ειδική διαρύθμιση χώρου"	"ειδικά προσαρμοσμένο περιβάλλον"

Table 4.1.1 (continued): List of major words or phrases from SCIM III, in Greek, that underwent review and changes during the translation process

Word in English	Options under consideration (in Greek) of the same word	Final chosen word in Greek
toilet wheelchair	(SCIM developers confirmed that a "tiolet wheelchair" is "a wheelchair specially designed to access the toilet room") "ενσωματωμένη τουαλέτα" or "καρότσι τουαλέτα"	"αναπηρικό αμαξιδίο τουαλέτας"
unable	"ανικανότητα" or "δεν μπορεί" or "στερείται ικανότητας"	"Στερούμαι ικανότητας"
Upper Body"	"Άνω μέρος σώματος" or "άνω κορμός"	"Άνω μέρος σώματος"
Wash independently	"Πλένεται ανεξάρτητα" or "ανεξάρτητος/-η με πλύσιμο"	"Πλένομαι ανεξάρτητα"
Washing (body)	"Πλύσιμο" or "ξέβγαλμα"	"πλύσιμο"
wearing	It was agreed with SCIM developers that the word "wearing" was not different to the word "dressing" (also used in the same sentence) therefore only the word "dressing" was translated	
With (meaning with the use of)	"με τη χρήση" or "χρησιμοποιώντας"	"Χρησιμοποιώντας"

Table 4.1.2 Feedback provided by the forward translators led to the following changes:

Changes made following translator's feedback
• Greeks may refer themselves as "Greeks" and "Mediterranean" and "East Europeans" and "Balkanians", therefore question 4 was changed so as not to have overlapping categories.
• In Greece only the metric system is used to measure distance and therefore the "miles" option was deleted (quest 9).
• The word "centre" was added in the "therapeutic horse riding" (quest 9).
• "Manual physiotherapy" was changed to "physiotherapy" to include the broader term of physiotherapy. Additionally, "exercises in the physiotherapy gym" was changed to "kinisiotherapy" to include any movement physiotherapy (quest 31).
• Abbreviations were added at the beginning of the questionnaire and on the header of each page to assist reading of the questions.

Table 4.1.3 Changes to the questionnaire following the UK pilot stage

• As the respondents were asked (quest 9) to state the distance of the therapeutic horse riding the option "Other centre of my interest" was added as some may have other therapy of their choice.
• Explanation on where the spinal segments are is added (quest 14).
• The option of "rehabilitations centre" does not necessarily mean that this is a SCI centre. Therefore the option "SCI centre" was added (quest 18).
• There may be a case where the respondent was initially treated in on hospital/centre and then transferred to another. For this reason all respondents are asked to give their total hospitalisation period (quest 20).
• Question 21 was simplified to be more users friendly.
• The option "every day" (quest 25) was added.
• The option "I did not feel pain while in hospital/centre was added (quest 20).
• The option "therapeutic horse riding" was removed from in hospital period treatments as no hospital offers such treatment.
• The formatting of questions 34 and 35 significantly changes to make the questions more users friendly.
• The author decided to include the distance from "pain clinic" (quest 9).

Table 4.1.4 Most important changes after the second pilot stage, given to the Greek group

• The language options "Spanish" and "French" were taken out and "Albanian" was put in as it is a more common language to speak in Greece (quest 2).
• As the Greek Higher Education System consists of both Universities and Technological Institutions, an option for the latest was added (quest 5).
• Question 7 was commented on a number of times and changes were made on the suggested working hours, the easiness to read and the number choices the respondent can choose.
• The format of question 9 was changed to make it more users friendly.
• The cause of injury was further expanded to include more options.
• Question 21 was further simplified. The respondents are now asked to state any surgery they may have had post their SCI related or not to their SCI.
• Question 23 was re-formatted to avoid being a double question.
• Question 25 was long to read and was therefore simplified.
• Where necessary the option "I don't remember" was added.

4.2 Rules and codes

4.2.1 Rules and codes; Socio-demographic questionnaire

4.2.1.1 Rules and codes; Socio-demographic questionnaire; design

In summary, the following rules found to assist questionnaire completion[342] were taken into account during the development of the survey:

1) Abbreviations on each current page were explained on the header of each paper or web page so the respondent did not have to look for them;

2) Double-barrelled questions were avoided;

3) No proverbs, negatives or leading questions were used;

4) Questions on sensitive topics were avoided, however some may claim that $q22_{44}$ could be a sensitive topic. For this reason the "do not want to say" option was added to give more flexibility to the respondent;

5) Instructions how to fill in the questionnaire were included throughout.

4.2.1.2 Rules and codes; Socio-demographic questionnaire; general

The most important rules formed for data entry and analysis for the socio-demographic part of the questionnaire were

1) If a respondent reported a range of working hours, then the mean of these hours was calculated to (e.g. 10-15 hours of work per week is 12.5 hours of work);
2) If a respondent reported "other type of injury" and explained this to be Cauda Equina or Brown Sequard Syndrome, then the type of injury was marked as an incomplete SCI as per ASIA International SCI classification[9];
3) If a respondent failed to report the date of completing the questionnaire, which was used in order to calculate the age of the participant and time since injury, this information was collected via the SurveyMonkey® functions which enables

[44] This question asked about friends and family support. See Appendix 2.

identification of this information. This option was applicable only for the online completed questionnaires.

4.2.2 Rules and codes; SF-MPQ and PRI

When a respondent did not tick all of the responses in the PRI of the SF-MPQ the following was taken into the account in order to decide if the lack of response should be marked as “truly” missing data or not:

1) If the respondent has not replied to all the descriptors and to those that s/he has replied the descriptor "none" was never selected (the respondent has only marked descriptors as "mild", "moderate", or "severe") this will indicate that s/he had only chosen to reply to the pain descriptor that s/he felt pain for. In this case this will not be treated as missing data and for the descriptors that s/he has not replied it will be assumed that no pain existed and the "none" response will be entered (by the researcher) and calculated as such.

2) If the respondent has replied to all/most of the variables but missed out some of them this will be considered as true missing data and calculated as such. If the respondent has selected the option "none" as a reply to some of the descriptors then this will be a stronger indication that s/he has understood that when a pain is not felt then the "none" option should be selected therefore failing to answer was due to lack of attention. "

3) If the respondent did not reply to the PRI at all (not a single descriptor was given a response) then this is considered to be true missing data and no response will be added by the researcher.

Prof. Melzack, developer of the McGill scale was consulted and his response was “*I agree with your distinction. It is very reasonable. It is rarely expressed so explicitly and clearly*” (Personal communication, 04/03/2010).

Appendix 5; Transalation and respondents' profiles

Supplement to Chapter 6; part 1

5.1: Translations

Table 5.1.1: Demographic profiles of forward translators used for the socio-demographic part of the questionnaire

Profiles	Responses	Mean±SD
Occupation	n=1 Occupational Therapist n=1 Physiotherapist n=1 Lecturer in Economics n=1 Business analyst n=1 Business PhD student	
Years living in the UK		7.7±5.2
Hours needed to complete the translation of the questionnaire		6.8±4.8
Use of dictionary	n=1 "yes, sometimes" n=3 "yes, but rarely" n=1 "no, it was easy to translate"	
Overall difficulty to translate		2.6±2.6*
Easiest question to translate	Questions 10, 16, 17, 24, and 51	0.4±0.5*
The most difficult question to translate	Question 29	4.6±3.0*

*On a NRS ranging from 0= very easy to translate to 10= the most difficult translation.

Abbreviation: SD, Standard Deviation; NRS, Numeric Rating Scale.

5.2.Bonferroni correction

Table 5.2.1: Main variables used in analysis of socio-demographic profile of respondents and alpha value set following Bonferroni correction.

Main Variable	Tests with following variables		Alpha value following Bonferroni correction
Pain (in general)	With itself Gender Cause of injury Age	5) Type of injury 6) Time since injury 7) (3) levels of injury	0.05/7=0.007 p≤0.007
Back pain	With itself Gender Cause of injury Age	5) Type of injury 6) Time since injury 7) (3) levels of injury	0.05/7=0.007 p≤0.007
Current LBP	With itself With MSKP Gender Cause of injury	5) Age 6) Type of injury 7) Time since injury 8) (3) levels of injury	0.05/8=0.006 p≤0.006
Lifetime LBP (post iSCI)	With itself With MSKP Gender Cause of injury	5) Age 6) Type of injury 7) Time since injury 8) (3) levels of injury	0.05/8=0.006 p≤0.006
LBP over last 1 month	With itself With MSKP Gender Cause of injury	5) Age 6) Type of injury 7) Time since injury 8) (3) levels of injury	0.05/8=0.006 p≤0.006
LBP over last 3 months	With itself With MSKP Gender With males With females	6) Cause of injury 7) Age 8) Type of injury 9) Time since injury 10) (3) levels of injury	0.05/10=0.005 p≤0.005
MSKP	With itself Gender With males With females Cause of injury	6) Age 7) Type of injury 8) Time since injury 9) (3) levels of injury 10) With pain days	0.05/10=0.05 p≤0.005

Abbreviations: MSKP, Musculoskeletal pain; LBP, Low back pain

5.3: Pain, MSKP and LBP prevalence

Table 5.3.1: Demographic profile characteristics

	Number of responses	%
Neuropathic pain		
Above level of injury		
Yes	19	9.7
No	176	90.3
At-level of injury		
Yes	64	32.8
No	131	67.2
Below-level of injury		
Yes	121	62.1
No	74	37.9
Upper limb pain		
Yes	40	79.5
No	155	20.5
Had a surgery following SCI		
Yes	139	63.8
No	79	36.2
Family and friends supportive		
Yes	166	76.1
No	6	2.8
Not as much as I need	36	16.5
I do not want their support	1	0.5
I do not need their support	6	2.6
I do not want to say	2	0.9
Other	1	0.5
Insurance used for SCI treatment		
National/ State/ Public	92	42.2
Private	71	32.6
Both national/state/public and private	22	10.1
None	6	2.8
Medicare	19	8.7
Other	8	3.7
First treated after SCI in a:		
National/ State/ Public hospital	113	51.8
Private hospital	72	33.0
National/State/Public rehabilitation centre	3	1.4
Private rehabilitation centre	7	3.2
National/State/Public SCI centre	5	2.3
Private SCI centre	5	2.3
Medical centre/trauma centre	6	2.8
Army hospital	4	1.8
Other	3	1.4

5.4: Pain, MSKP and LBP; relation to demographic profile

Table 5.4.1: Percentage of males and females reporting the pain categories and statistical differences in the pain presence between gender

	Males %, n total	**Females** %, n total	**Statistical Test**
Pain in general	91, n=134	93.8, n=81	χ^2=0.53, df1, p=0.46
MSKP	32.6, n=132	48.7, n=78	χ^2=5.392, df1, p=0.02*
Back pain	75, n=132	82.1, n=78	χ^2=31.4, df1, p=0.23
Lifetime LBP	69.4, n=134	81.5, n=81	χ^2=3.82, df1, p=0.051
Current (point) LBP	64.9, n=131	75, n=77	χ^2=1.87, df1, p=0.17
1 month LBP	64.1, n=131	76.6, n=77	χ^2=4.78, df1, p=0.06
3 months LBP	65.6, n=131	78.9, n=76	χ^2=4.02, df1, p=0.04*

Females reported higher frequencies on all categories of pain compared to males. No significant difference existed post application of the Bonferroni correction for the total group or when people without pain in general were excluded.
*Not passing Bonferroni correction.
Abbreviations: MSKP, Muskuloskeletal pain; LBP, Low Back Pain.
Statistical test: χ^2, Pearson's chi-square.

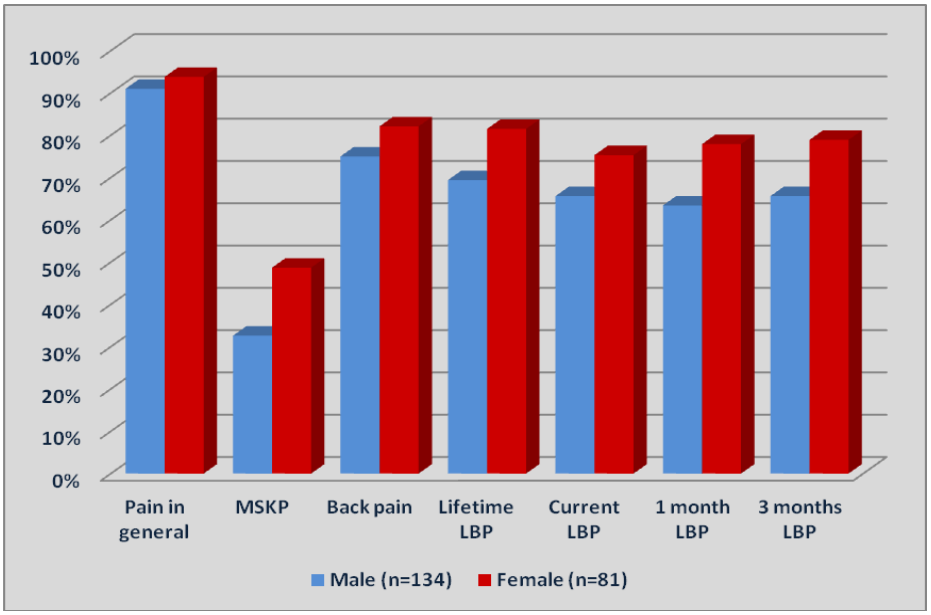

Figure 5.4.1: Percentage of men and women reporting the pain categories
Abbreviations: MSKP, Musculoskeletal pain; LBP, Low back pain.

Table 5.4.2: Within people with pain only, percentage of males and females reporting the pain categories and differences in pain presence between gender

	Males %, n total	**Females** %, n total	**Statistical Test**
MSKP	35.8, n=120	52.1, n=73	χ^2=4.90, df1, p=0.02[1]
Back pain	82.5, n=120	87.7, n=73	χ^2=0.92, df1, p=0.33
Lifetime LBP	76.2, n=122	86.8, n=76	χ^2=3.33, df1, p=0.06
Current (point) LBP	71.4, n=119	79.2, n=72	χ^2=1.40, df1, p=0.23
1 month LBP	70.6, n=119	81.9, n=72	χ^2=3.07, df1, p=0.08
3 months LBP	72.3, n=119	84.5, n=71	χ^2=3.74, df1, p=0.053

[1]not significant post Bonferroni correction;
Abbreviations: MSKP, Muskuloskeletal pain; LBP, Low Back Pain.
Statistical test: χ^2, Pearson's Chi-square.

Table 5.4.3: Differences in the proportion of pain within males and within females

	Within Males Statistical Test	**Within Females** Statistical Test
MSKP	Yes n=43, No n=89 χ^2=16.03 **p≤0.001*****	Yes n=38, No n=39 χ^2=0.01 p=0.29
3 months LBP	Yes n=86, No n=45 χ^2=12.82 **p≤0.001*****	Yes n=60, No n=16 χ^2=25.47 **p≤0.001*****
Correlation between MSKP & LBP over 3 months	n=128 ϕ=0.17 p=0.42	n=75 ϕ=0.39 **p≤0.001*****

Within both males and females significantly more people reported having LBP over the last 3 months but only within males significantly more people reported not having MSKP. Within females a significant association existed between MSKP and LBP.
***Significant at p≤0.001 level;
in bold: singificant following application of the Bonferroni correction
Abbreviations: MSKP, Muskuloskeletal pain; LBP, Low Back Pain
Statistical test: χ^2, goodness of fit Chi-square.

Table 5.4.4: Percentage of people with traumatic and non-traumatic injury reporting the pain categories. Differences in pain presence between groups divided by cause of injury

	Traumatic %, n total	**Non-traumatic** %, n total	**Statistical Test**
Pain in general	91, n=141	92.2, n=64	χ^2=0.08, df1, p=0.77
MSKP	34, n=150	50, n=64	χ^2=4.83, df1, p=0.02 [1]
Back pain	74, n=150	84.4, n=64	χ^2=2.73, df1, p=0.09
LBP life time	69.7, n=155	82.8, n=64	χ^2=4.01, df1, p=0.04 [1]
LBP current	63.5, n=148	78.1, n=64	χ^2=4.37, df1, **p=0.003****
LBP last 1 month	64.2, n=148	78.1, n=64	χ^2=4.01, df1, p=0.04 [1]
LBP last 3 months	66, n=147	79.7, n=64	χ^2=3.97, df1, p=0.04 [1]

[1]not significant post Bonferroni correction; **Significant at p≤0.01 level,
in bold: significant following application of the Bonferroni correction
Abbreviations: MSKP, Muskuloskeletal pain; LBP, Low Back Pain
Statistical test: χ^2, Pearson's chi-square

Table 5.4.5: Within people with pain only, percentage of people with traumatic and non-traumatic injury reporting the pain categories. Differences in the pain presence between groups divided by cause of injury

	Traumatic %, n total	**Non-traumatic** %, n total	**Statistical Test**
MSKP	37.5, n=136	54.2, n=59	χ^2=4.71, df1 p=0.03 [1]
Back pain	81.6, n=136	91.5, n=59	χ^2=3.10, df1 p=0.07
LBP life time	76.6, n=141	89.8, n=59	χ^2=4.64, df1 p=0.03 [1]
LBP current	70.1, n=134	84.7, n=59	χ^2=4.60, df1 p=0.03[1]
LBP last 1 month	70.9, n=134	84.7, n=59	χ^2=4.20, df1 p=0.04 [1]
LBP last 3 months	72.9, n=133	86.4, n=59	χ^2=4.22, df1 p=0.04 [1]

[1]not significant post Bonferroni correction;
Abbreviations: MSKP, Muskuloskeletal pain; LBP, Low Back Pain
Statistical test: χ^2, Pearson's chi-square

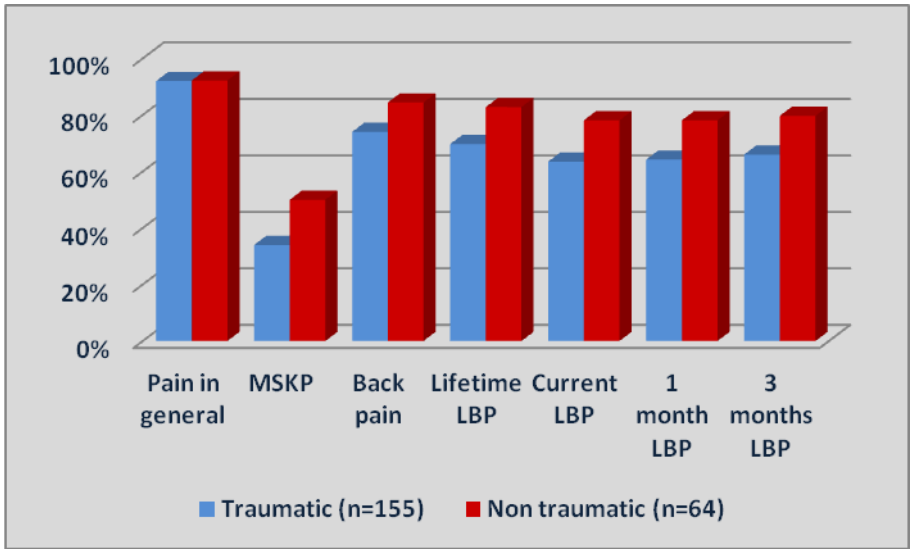

Figure 5.4.2: Percentage of people reporting the pain categories divided into groups by cause of injury.
Abbreviations: MSKP, Musculoskeletal pain; LBP, Low back pain.

Table 5.4.6: Percentage of people with tetraplegia and paraplegia reporting the pain categories. Differences in pain presence between groups divided by cause of injury

	Tetraplegia %, n total	**Paraplegia** %, n total	**Statistical Test**
Pain in general	Tetraplegia 87.4, n=103	Paraplegia 94.8, n=116	χ^2= 3.28, df1 p=0.51
MSKP	Tetraplegia 33, n=100	Paraplegia 43.9, n=114	χ^2= 2.64, df1 p=0.10
Back pain	Tetraplegia 67 , n=100	Paraplegia 86, n=114	χ^2= 10.85, df1 **p≤0.001*** **
LBP lifetime	Tetraplegia 62.1, n=103	Paraplegia 83.6, n=116	χ^2= 12.93, df1 **p≤0.001*** **
LBP current	Tetraplegia 57.6, n=99	Paraplegia 77, n=113	χ^2= 9.13, df1 **p=0.003****
LBP 1 month	Tetraplegia 57.6, n=99	Paraplegia 77.9, n=113	χ^2= 10.06, df1 **p=0.002****
LBP 3 months	Tetraplegia 57.6, n=99	Paraplegia 81.3, n=113	χ^2= 14.06, df1 **p≤0.001*** **

People with paraplegia reported higher percentages of all categories of pain and often there was a significant difference between people with and without the pain categories (see also Table 5.4.7).
[1]not significant post Bonferroni correction; ***Significant at p≤0.001 level,
in bold: significant following application of the Bonferroni correction
Abbreviations: MSKP, Muskuloskeletal pain; LBP, Low Back Pain
Statistical test: χ^2, Pearson's hi-square

Table 5.4.7: Within people with pain, percentage of the pain categories reported by people divided into groups by level of injury and difference in the pain presence between people with tetraplegia and paraplegia.

	Tetraplegia %, n total	**Paraplegia** %, n total	**Statistical Test**
Pain in general	Tetraplegia 54, n=200	Paraplegia 55, n=200	N/A
MSKP	Tetraplegia 37.9, n=87	Paraplegia 46.3, n=103	χ^2= 1.37, df1 p=0.24
Back pain	Tetraplegia 72.4, n=87	Paraplegia 88.9, n=108	χ^2= 6.97, df1 p=0.008[1]
LBP lifetime	Tetraplegia 71.1, n=90	Paraplegia 88.2, n=110	χ^2= 9.18, df1 **p=0.002****
LBP current	Tetraplegia 66.3, n=86	Paraplegia 81.3, n=107	χ^2= 5.93, df1 p≤0.01[1]
LBP 1 month	Tetraplegia 66.3, n=86	Paraplegia 82.2, n=107	χ^2= 6.50, df1 p≤0.01[1]
LBP 3 months	Tetraplegia 66.3, n=86	Paraplegia 85.8, n=106	χ^2= 10.29, df1 **p≤0.001*****

[1]not significant post Bonferroni correction; ***Significant at p≤0.001 level, **in bold:** significant following application of the Bonferroni correction.
Abbreviations: MSKP, Muskuloskeletal pain; LBP, Low Back Pain.
Statistical test: χ^2= Chi-square.

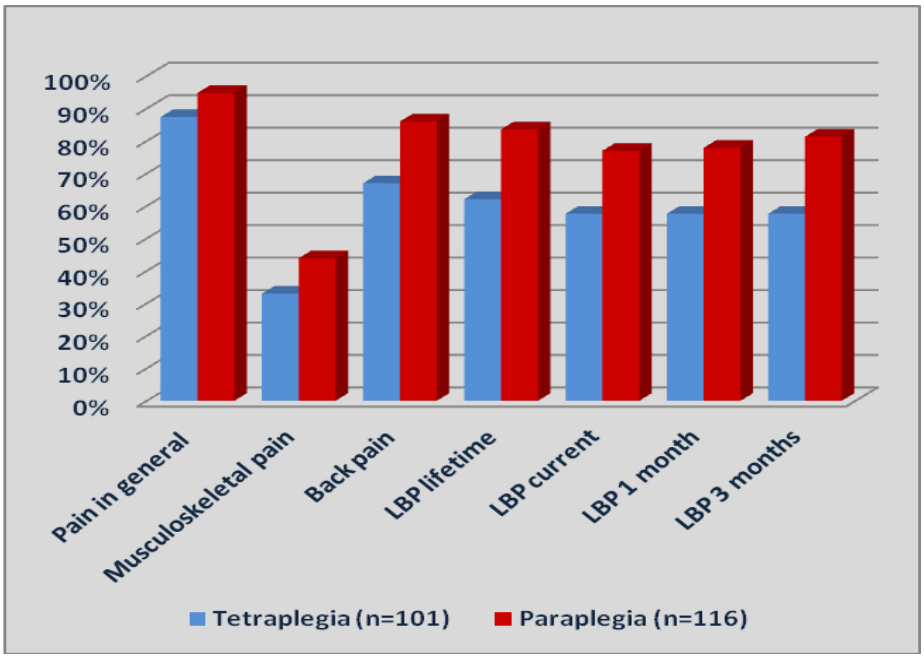

Figure 5.4.3: Percentage of people reporting the categories of pain divided in groups by type of injury
Abbreviations: LBP, Low back pain.

Table 5.4.8: Percentage of pain categories reported by people divided into groups by the level of injury. Differences in pain presence between groups

	Level of injury – total sample, %, n total		Statistical Test	Level of injury – among people with pain only, %, n total		Statistical Test
Pain in general	Cervical Thoracic Lumbar	87.4 n=103 93.2 n=73 97.7 n=43	χ^2=4.52, df2 p=0.10	N/A		N/A
MSKP	Cervical Thoracic Lumbar	33 n=100 37.5 n=72 54.8 n=42	χ^2=5.97, df2 p=0.05[1]	Cervical Thoracic Lumbar	37.9 n=87 40.3 n=67 56.1 n=41	χ^2=3.97, df2 p=0.13
Back pain	Cervical Thoracic Lumbar	67 n=100 81.9 n=72 92.8 n=42	χ^2=12.64, df2 **p=0.002****	Cervical Thoracic Lumbar	77 n=87 88 n=67 95.1 n=41	χ^2=7.95, df2 p≤0.01[1]
LBP lifetime	Cervical Thoracic Lumbar	62.1 n=103 78.1 n=73 93 n=43	χ^2=16.03, df2 **p<0.001*****	Cervical Thoracic Lumbar	72.4 n=87 85.1 n=67 95.1 n=41	χ^2=11.34, df2 **p≤0.003****
LBP current	Cervical Thoracic Lumbar	57.6 n=99 74.6 n=71 81 n=42	χ^2=9.61, df2 p=0.008[1]	Cervical Thoracic Lumbar	66.3 n=86 80.3 n=66 82.9 n=41	χ^2=5.77, df2 p=0.056
LBP 1 month	Cervical Thoracic Lumbar	57.6 n=99 74.6 n=71 83.3 n=44	χ^2=10.98, df2 **p=0.004****	Cervical Thoracic Lumbar	66.3 n=86 80.3 n=66 85.4 n=41	χ^2=6.85, df2 p=0.03[1]
LBP 3 months	Cervical Thoracic Lumbar	57.6 n=99 77.5 n=71 87.8 n=41	χ^2=15.39, df2 **p<0.001*****	Cervical Thoracic Lumbar	66.3 n=86 83.3 n=66 90 n=40	χ^2=10.92, df2 **p=0.004****

[1]not significant post Bonferroni correction; **Significant at p≤0.01 level, ***Significant at p≤0.001 level, **in bold:** significant following application of the Bonferroni correction
Abbreviations: MSKP, Muskuloskeletal pain; LBP, Low Back Pain
Statistical test: χ^2, Pearson's Chi-square

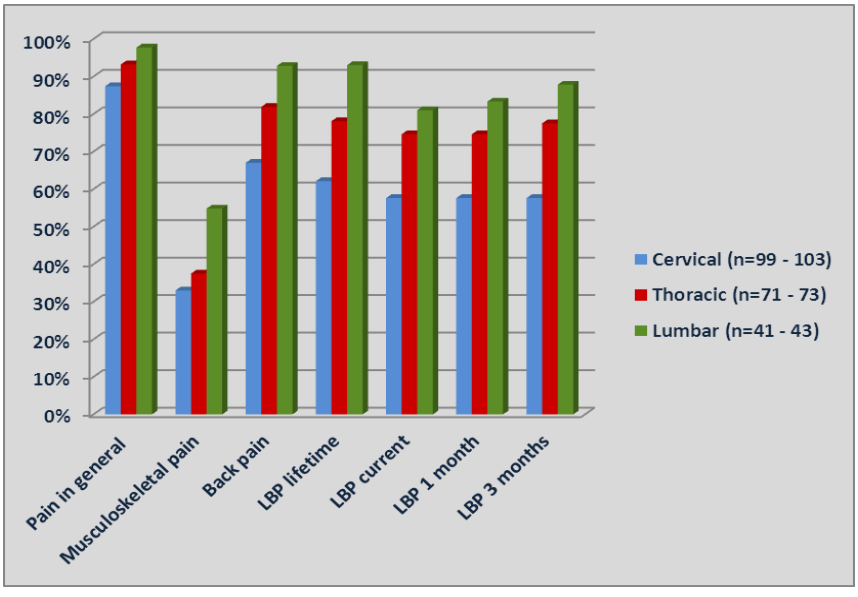

Figure 5.4.4: Percentage of people reporting the categories of pain divided into groups by level of injury
Abbreviations: LBP, Low Back Pain

Table 5.4.9: Two group differences in MSKP reported by people divided into groups by level of injury

MSKP		Thoracic level	Lumbar Level
	Cervical Level	p=0.54	p=0.015*
	Thoracic Level		p=0.073
BP		Thoracic level	Lumbar Level
	Cervical Level	p=0.029*	p≤0.001***
	Thoracic Level		p=0.10
Lifetime LBP		Thoracic level	Lumbar Level
	Cervical Level	p=0.040*	p≤0.001***
	Thoracic Level		p=0.036*
Current LBP		Thoracic level	Lumbar Level
	Cervical Level	p=0.008**	p=0.008**
	Thoracic Level		p=0.44
LBP over last 1 month		Thoracic level	Lumbar Level
	Cervical Level	p=0.02*	p<0.03*
	Thoracic Level		p=0.28
LBP over last 3 months		Thoracic level	Lumbar Level
	Cervical Level	p=0.07*	p≤0.01***
	Thoracic Level		p=0.17

Two group comparisons showed that people with a lumbar level injury reported significantly more often MSKP, LBP and BP than people with a cervical injury. Equally, people with a thoracic injury reported significantly higher percentage of LBP presence than people with cervical injuries.
*Significant at p≤0.05 level;
Abbreviations: MSKP, Muskuloskeletal pain; BP, Back Pain; LBP, Low Back Pain
Statistical test: χ^2, Pearson's chi-square

5.5: Pain and LBP; relation to pain/LBP days, free periods, onset

Table 5.5.1: Percentage of people reporting the number of pain and LBP days felt per month

Average pain days per month	**Pain in general** %, total n=195	**LBP** %, total n=195, n=156 [1]
1-9 days per month	14.4	21 26.3
10-20 days per month	14.4	14.3 17.9
21-30 days per month	9.7	9.2 11.5
Have pain every day	61.5	35.4 44.2
No LBP	n/a	20

[1]After removing the group with no LBP
Abbreviation: LBP, Low Back Pain

Table 5.5.2: Percentage of people with and without MSKP and the number of their reported pain days felt per month. Difference in their number of pain days between people with and without MSKP

	1-9 days %	10 – 20 days %	21 – 30 days %	Every day %	Statistical Test
Pain including MSKP (n=83)	10.8 n=9	18.1 n=15	8.4 n=7	62.7 n=52	χ^2=4.91, df3 p=0.40
Pain but no MSKP (n=112)	17 n=19	11.6 n=13	10.7 n=12	60.7 n=68	

People without any pain in general were excluded from analysis
Abbreviations: MSKP, Musculoskeletal pain
Statistical test: χ^2, Chi-Square

Table 5.5.3: Percentage of people reporting frequency of pain and LBP free weeks

Since pain/LBP started have you had 1 week or more or pain free period?	Pain in general % n=185	*LBP % ,n=123
Yes, most of the time	9.2	13.8
Yes frequently	9.7	7.3
Yes, sometimes	10.8	11.4
Yes, but not very often	7	8.9
Yes, but rarely	11.4	19.5
No, I always have pain	51.9	39

*Excluding people who did not remember and those who do not feel LBP
Abbreviation: LBP, Low Back Pain

Table 5.5.4: Percentage of people reporting time of pain and LBP onset post iSCI

Pain onset	Pain onset % n=187	LBP onset % n=144
Immediately after SCI	41.7	32.6
Within the 1st month post SCI	19.3	15.3
Between 1-6 months post SCI	20.3	18.7
Between 6 months & 1 year post SCI	6.4	9.7
After 1 year post SCI	12.3	22.2

People with no pain or LBP and those who did not remember the onset of their pain or LBP were excluded
Abbreviation: LBP, Low Back Pain

Appendix 6; Pain extent and LBP experience

Supplement to Chapter 6; part 2

6.1: Bonferroni Correction

Table 6.1.1: Main variables used in analysis of MPQ and alpha value set following Bonferroni correction.

Main Variables	Tests with following variables		Alpha value following Bonferroni correction
S-PRI A-PRI T-PRI Intensity of current LBP Intensity of LBP over 1 month Intensity of LBP over 3 months PPI of LBP	1) With gender With cause of injury With age With type of injury With cause of injury With time since injury	7) With areas with pain 8) With pain days 9) With LBP days 10) With pain free weeks 11) With LBP free weeks 12) With pain onset 13) With LBP onset	0.05/13=0.0038 p≤0.0038

Abbreviations: EQ-5D index, Quality of Life index; EQ-VAS, Quality of Life Visual Analogue Scale; MSKP, Musculoskeletal Pain; LBP, Low Back Pain; PRI, Present Rating Index.

6.2: Pain extent; general results

In Figure 6.2.1 it is noticed that most people felt pain in two areas on their body (13.8%). This was closely followed by those reporting three areas with pain (12.8%). One person reported 41 areas and another one 45 areas making them extreme values in the sample (not shown in graph). When these two respondents were removed from the analysis the mean number of areas with pain dropped slightly to 7.44 (±6.05) but the median and the mode remained the same.

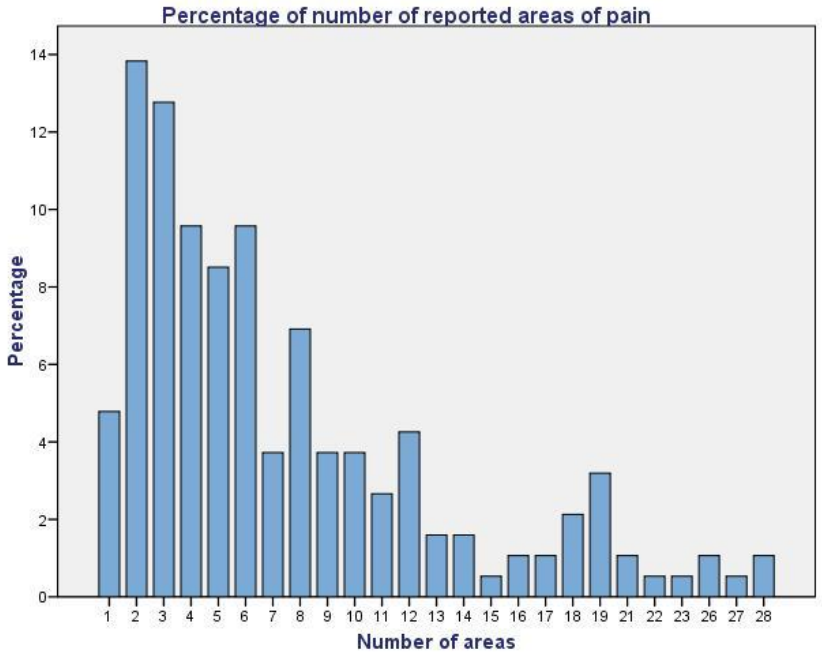

Figure 6.2.1: Percentage of people reporting the number of areas with pain on the body chart divided into 45 areas. Division was according to Margolis et al{{738 Margolis, R.R 1986}}

6.2.1: Pain extent; general results; NRS vs VAS

A brief analysis to identify possible reasons for the observed differences in the mean intensity scores of people while using the NRS or the VAS showed some differences. These differences were in the mean scores of the Greek group (using the VAS) compared to the UK and USA groups (using the NRS) for LBP intensity over the last 1 and 3 months. This finding implied that nationality could have been a factor affecting the results. The respondents who completed the VAS mainly had a non-traumatic cause for their injury but further analysis did not reveal that this could be the reason for this difference. Further analysis would have been needed to identify the exact factors affecting these results. But, as this was beyond the aim of this study it was decided that it would have been inappropriate to pool together and analyse the above data. Consequently, only the data collected using the NRS, which was the largest of the two groups, were included in the analysis.

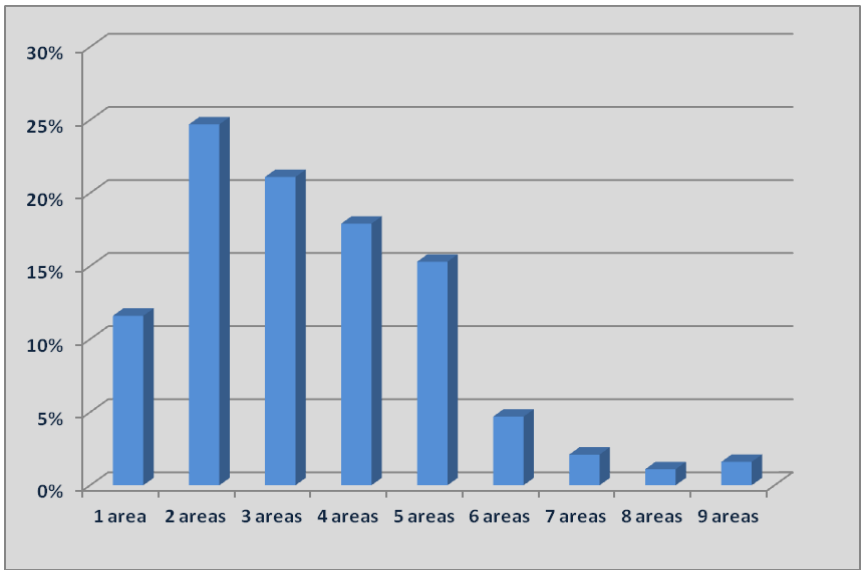

Figure 6.2.2: Percentage of people reporting from 1 to 9 areas with pain. n=190

Table 6.2.1: Percentage of people reporting internal and external pain in the area of the back

	Internal pain (%)	External pain (%)	Both internal and external pain (%)	Pain not described/other (%)	Total (%)
Upper back - right side (n=190)	3.2	1	4.2	2.6	11
Upper back – midline (n=189)	9.5	1.6	5.8	1.1	18
Upper back – left side (n=190)	2.6	1.6	3.7	2.1	10
Lower back – right side (n=132)	19.7	2.3	8.3	3.8	34.1
Lower back – midline (n=132)	31.1	5.3	13.6	7.6	57.6
Lower back – right side (n=132)	18.9	3.0	9.8	3.8	35.5

6.3: Pain extent; relation to demographic profile characteristics

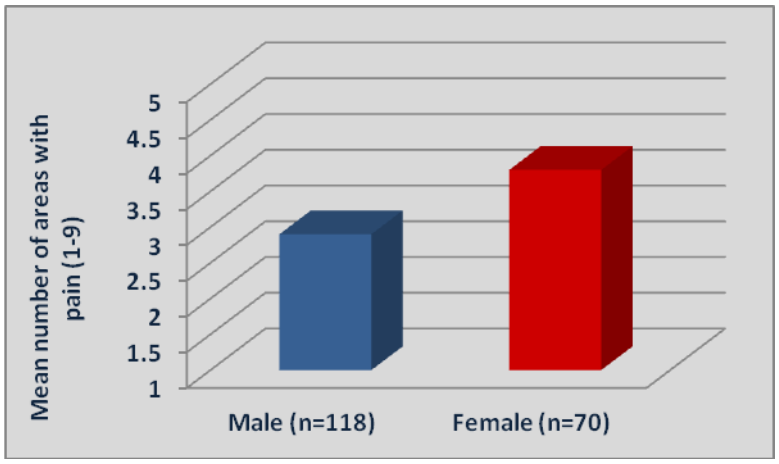

Figure 6.3.1: Mean number of areas with pain reported by males and females

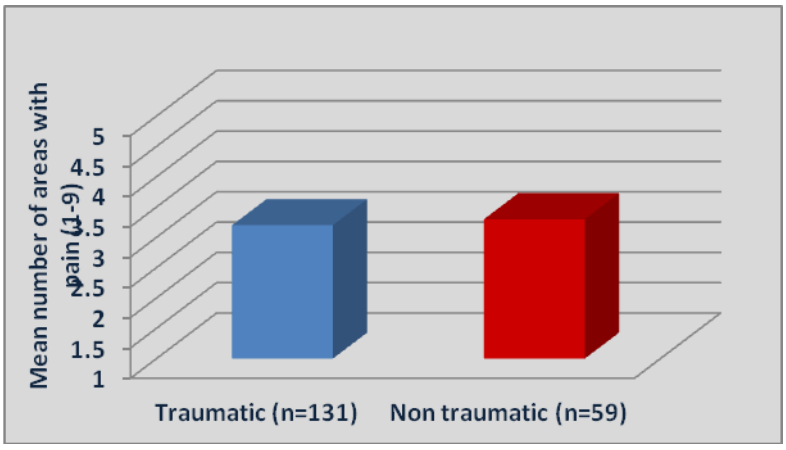

Figure 6.3.2: Mean number of areas with pain reported by people with traumatic and non-traumatic cause of injury.

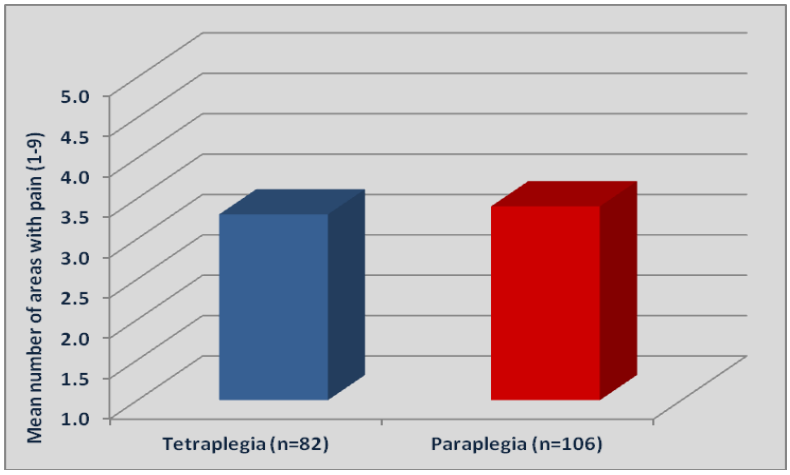

Figure 6.3.3: Mean number of areas with pain reported by people with tetraplegia and paraplegia

Table 6.3.1: Mean number of areas with pain in groups divided by level of injury

	Cervical mean±SD, median, min-max	**Thoracic** mean±SD, median, min-max	**Lumbar** mean±SD, median, min-max	**Statistical test**
Pain areas	3.3±1.9 3, 1-9 n=84	3.2±1.4 3, 1-7 n=64	3.3±1.3 3, 1-6 n=39	H=0.78, df2 p=0.67

Four outliers were eliminated.
Abbreviation: SD, Standard Deviation.
Statistical test: H, Kruskall-Wallis H test.

6.4: Pain extent; relation to pain/LBP days, free periods, onset

Table 6.4.1: Mean number of areas with pain in groups divided by the number of pain or LBP days per month

		1-9 days mean±SD, median, min-max	**10-20 day mean±SD, median, min-max**	**21-30 days mean±SD, median, min-max**	**Every day mean±SD, median, min-max**
Number of areas with pain	**Pain days**	2.4±1.2 2, 1-5 n=27	2.4±0.7 2, 1-4 n=21	3.1±1.4 3, 1-7 n=18	3.7±1.7 4, 1-9 n=116
	LBP days	3.6±1.4 3, 1-7 n=38	3.4±1.0 3, 2-5 n=24	3.9±1.9 4, 1-7 n=17	3.9±1.5 4, 1-8 n=64

Seven outliers were eliminated.
Abbreviation: LBP; Low Back Pain; SD, Standard Deviation.

Table 6.4.2: Mean number of areas with pain in groups divided by the frequency of pain and LBP breaks

	Yes, most time mean±SD, median, min-max	**Yes, frequently** mean±SD, median, min-max	**Yes, sometimes** mean±SD, median, min-max	**Yes, but not often** mean±SD, median, min-max	**Yes, but rarely** mean±SD, median, min-max	**No, I always have pain** mean±SD, median, min-max
Pain free weeks[1]	2.3±0.9 2, 1-4 n=14	2.9±0.8 3, 1-5 n=15	2.8±1.1 3, 1-5 n=19	2.7±0.9 3, 1-4 n=12	3.2±1.8 2.5, 1-7 n=20	3.7±1.8 4, 1-9 n=91
LBP free weeks[2]	3.2±0.9 3, 2-5 n=15	3.6±1.0 4, 2-5 n=7	3.7±2.7 3.5, 1-6 n=12	3.1±0.4 3, 2-4 n=8	3.3±2.8 3, 2-8 n=22	4.2±1.5 4, 2-8 n=46

[1]Six outlier eliminated, [2]Eight outliers eliminated.
Abbreviations: SCIM, Spinal Cord Independence Measure; SD, Standard Deviation; LBP, Low Back Pain.

Table 6.4.3: Mean number of areas with pain in groups divided by the time of onset of pain or LBP post iSCI

		Immediately after iSCI mean±SD, median, min-max	**Within the 1st month post iSCI** mean±SD, median, min-max	**Between 1-6 months post iSCI** mean±SD, median, min-max	**Between 6 months & 1 year post iSCI** mean±SD, median, min-max	**After 1 year post iSCI** mean±SD, median, min-max
Total number areas with pain	**Pain post iSCI**	3.7±1.9 4, 1-9 n=75	3.1±1.3 3, 1-6 n=35	3.0±1.4 3, 1-7 n=37	3.0±1.2 3, 1-5 n=12	3.1±1.8 3, 1-7 n=21
	LBP post iSCI	3.8±1.6 4, 1-8 n=45	3.5±1.4 4, 1-6 n=21	3.5±1.4 3, 2-7 n=27	3.7±1.7 4, 1-8 n=13	3.6±1.8 3, 1-9 n=29

Abbreviation: LBP, Low Back Pain; SD, Standard Deviation.

6.5: LBP quality and intensity; general results andrelation to demographic profile

Table 6.5.1: Rank values of LBP descriptors

LBP descriptors	n (total n=152)	SUM	Median	Mean	SD
Throbbing	149	115	0	0.8	1.1
Shooting	151	139	0	0.9	1.1
Stabbing	149	150	0	1.0	1.2
Sharp	150	169	1	1.1	1.2
Cramping	150	118	0	0.8	1.0
Gnawing	152	150	1	1.0	1.0
Hot-burning	149	155	1	1.0	1.1
Aching	151	234	2	1.5	1.1
Heavy	150	125	0	0.8	1.0
Tender	150	123	0	0.8	1.1
Splitting	147	77	0	0.5	0.9
Tiring-exhausting	151	197	1	1.3	1.2
Sickening	150	98	0	0.6	1.0
Fearful	151	84	0	0.6	0.9
Punishing-cruel	152	134	0	0.9	1.1
Total Sensory (range 0-33)	152	1555	8	10.2	7.8
Total Affective (range 0-12)	152	513	2	3.4	3.5
Total (S+A) (range 0-45)	149	2068	10.5	13.6	10.8

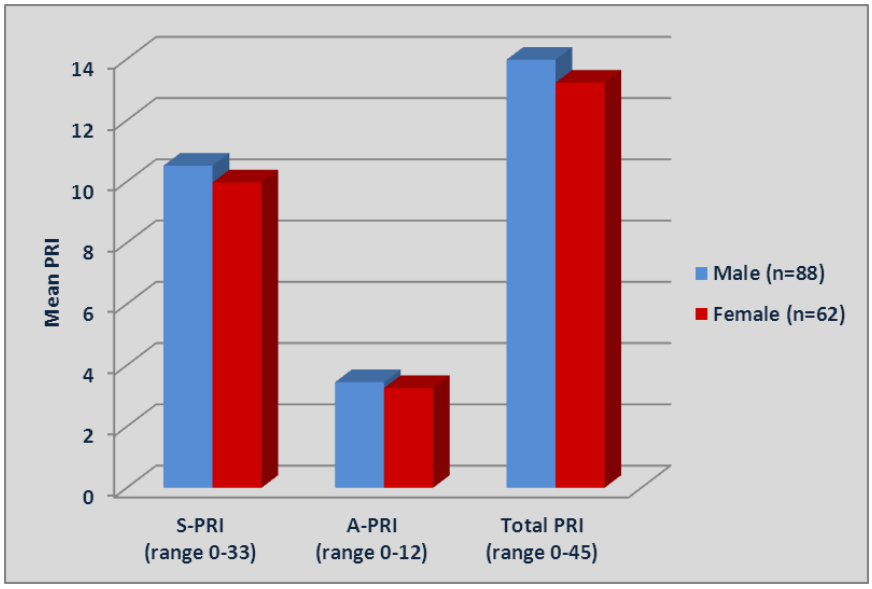

Figure 6.5.1: Mean LBP quality reported by men and women.
Abbreviation: PRI, Pain Rating Index; S-PRI, Sensory PRI; A-PRI, Affective PRI

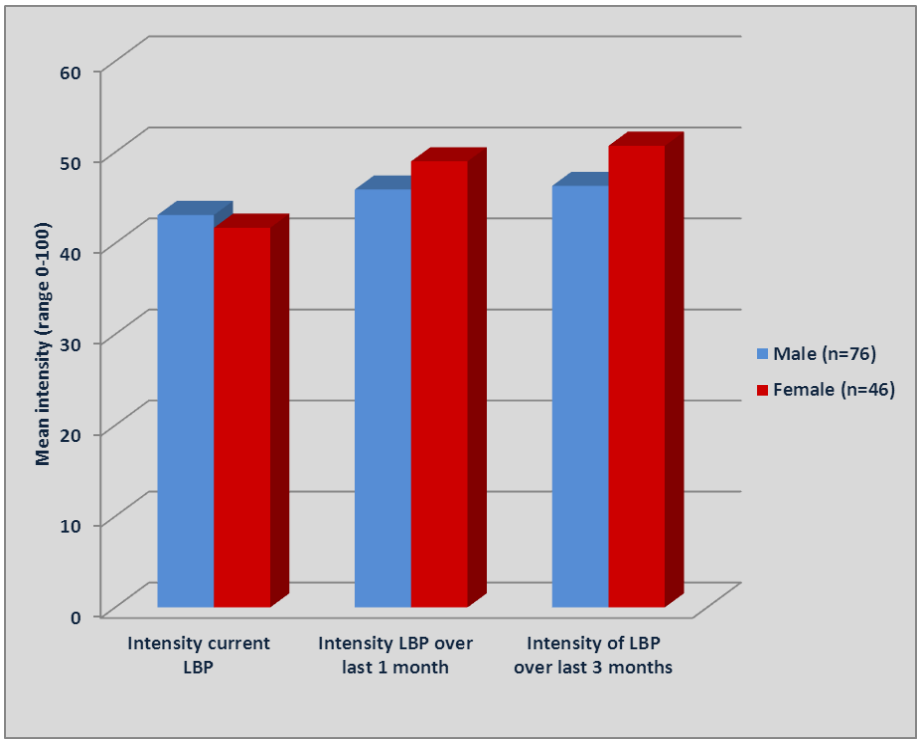

Figure 6.5.2: Mean LBP intensity reported by men and women.
Abbreviation: LBP, Low Back Pain

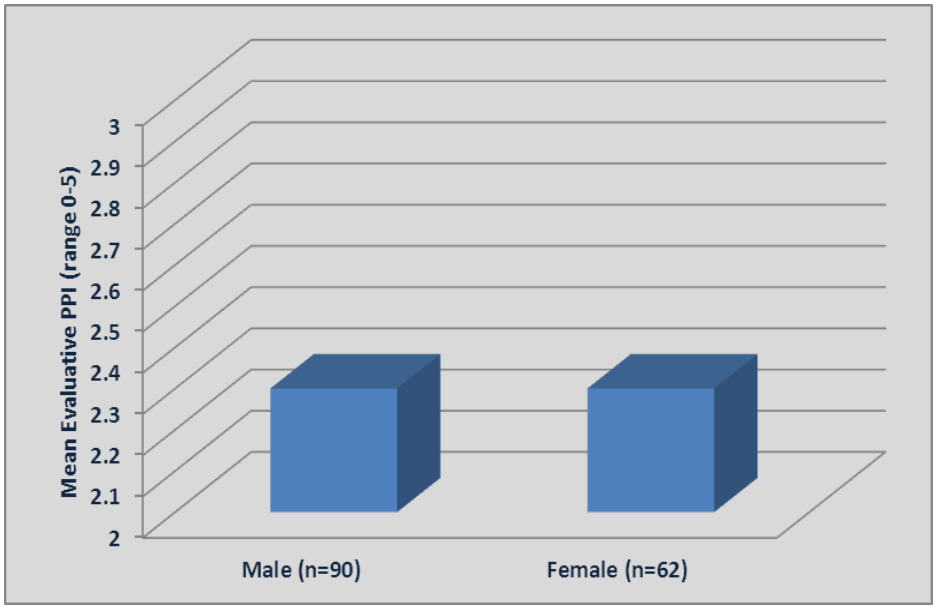

Figure 6.5.3: Mean LBP evaluative overall intensity reported by men and women.
Abbreviation: PPI, Present Pain Intensity

Table 6.5.2: Mean LBP quality and intensity in men and women. Differences in mean reports between gender

	Male mean±SD, min-max,	Female mean±SD, min-max,	Statistical Tests
S-PRI (range 0-33)	10.5±7.9, 0-33 n=88	9.7±7.8, 0-30 n=62	t=0.65, df148, p=0.67 95% CI -1.69, 3.34
A-PRI (range 0-12)	3.4±3.6, 0-12 n=88	3.3±3.5, 0-12 n=62	t=0.33, df148 p=0.74 95% CI -0.96, 1.36
Total PRI (range 0-45)	13.4±10.8, 0-45 n=88	12.8±10.9, 0-41 n=62	t=0.34, df145 p=0.70 95% CI -2.78, 3.96
Intensity for current LBP	43.1±28.0, n=76 0-100	41.7±29.1, n=46 0-97	t=0.25, df120 p=0.79 95% CI -9.1, 11.9
Intensity for LBP over last 1 month	45.9±27.0., n=76 0-95	49.0±27.0, n=46 0-98	t=-0.61, df120 p=0.54 95% CI -13.2, 6.9
Intensity for LBP over last 3 months	46.3±26.7, n=76 0-100	50.7±27.1, n=45 0-95	t=-0.86, df119 p=0.39 95% CI =-14.3, 5.6
PPI evaluative for LBP	2.5±1.2, n=90 0-5	2.4±1.1, n=62 1-5	t=0.02, df150, p=0.98 95% CI -0.4, 0.4

Two people did not reported their gender.
Abbreviations: PRI, Pain Rating Index; S-PRI, Sensory-PRI; A-PRI, Affective PRI; PPI, Present Pain Intensity; LBP, Low Back Pain.
Statistical tests: t, independent t-test.

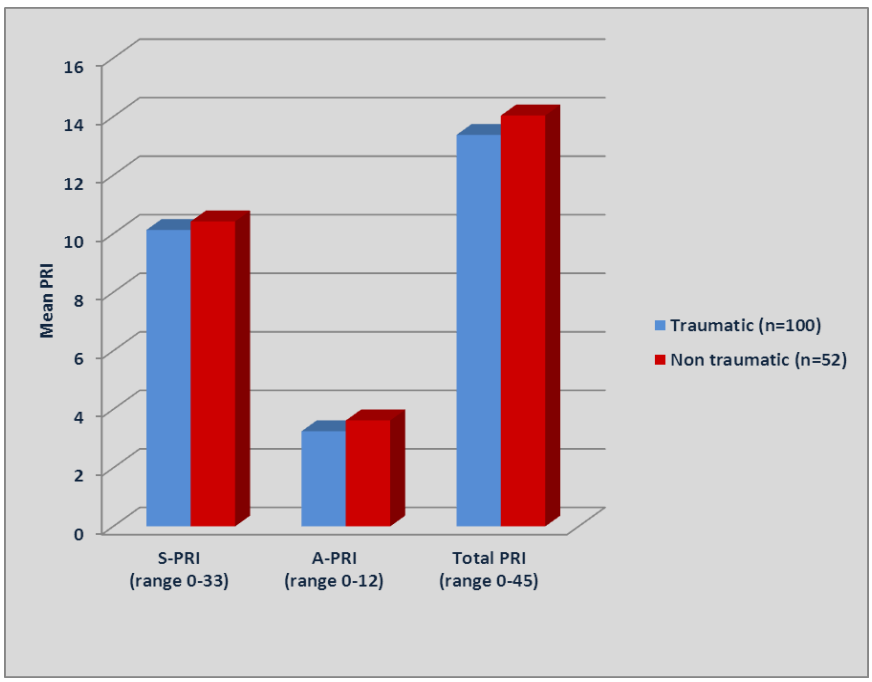

Figure 6.5.4: Mean LBP quality in groups divided by cause of injury. Abbreviations: PRI, Pain Rating Index; S-PRI, Sensory-PRI; A-PRI, Affective PRI; PPI, Present Pain Intensity.

Table 6.5.3: Mean LBP quality and intensity in groups divided by cause of injury and between group differences

	Traumatic mean±SD, min-max	Non traumatic mean±SD, min-max	Statistical test
S-PRI (range 0-33)	10.1±8.3, 0-33, n=100	10.4±6.9, 0-26 n=52	t=-0.21, df150 p=0.82, 95% CI -2.9, 2.3
A-PRI (range 0-12)	3.2±3.6, 0-12 n=100	3.6±3.5, 0-12 n=52	t=-0.6, df150 p=0.99, 95% CI -1.7, 0.8
Total PRI (range 0-45)	13.4±11.4, 1-45 n=100	14.0±9.5, 1-38 n=52	t=0.72, df150 p=0.20, 95% CI -4.3, 3.0
Intensity for current LBP	42.1±28.6, n=90 0-100	44.0±28.0, 0-97 n=32	t=0.32, df120 p=0.74, 95% CI -13.5, 9.7
Intensity for LBP over last 1 month	45.5±27.4 0-95 n=90	51.4±26.2 0-98 n=32	t=-1.04, df120 p=0.29, 95% CI -16.9, 5.2
Intensity for LBP over last 3 months	46.5±26.7 0-97 n=92	51.8±27.3 0-100 n=47	t=-0.94, df119 p=0.34, 95% CI =-16.2, 5.7
PPI evaluative for LBP[1]	2.2±0.9 1-4	2.3±0.8 0-4	t= -0.61, df140 p=0.53, 95% CI -0.41, 0.21

Abbreviations: PRI, Pain Rating Index; S-PRI, Sensory PRI; A-PRI, Affective PRI; PPI, Present Pain Intensity; LBP, Low Back Pain.
Statistical tests: t= independent t-test.

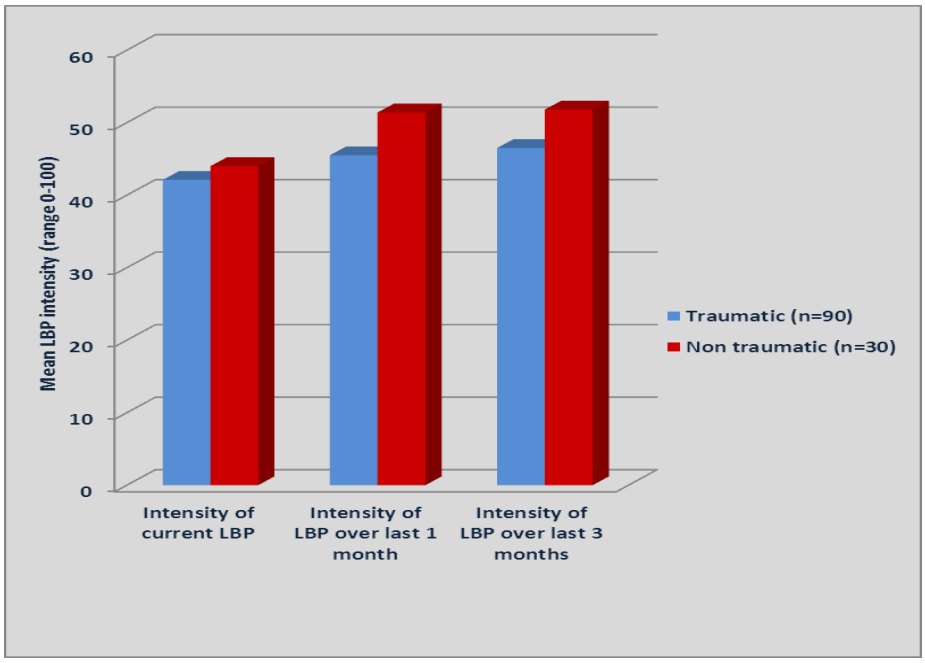

Figure 6.5.5: Mean LBP intensity in groups divided by cause of injury.

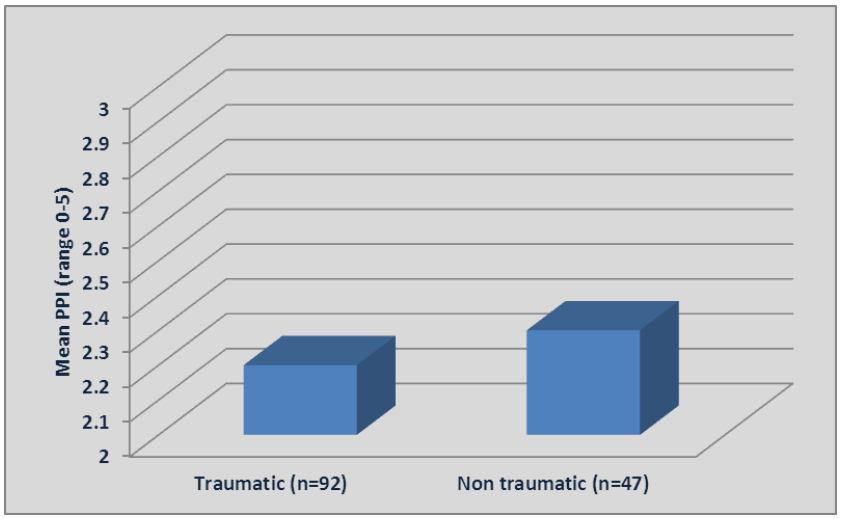

Figure 6.5.6: Mean LBP evaluative overall intensity in groups divided by cause of injury.

Table 6.5.4: Quality and intensity of LBP in groups divided by level of injury

	Cervical mean±SD, min-max, n	**Thoracic** mean±SD, min-max, n	**Lumbar** mean±SD, min-max, n
S-PRI (range 0-33)	7.5±5.6, 0-26, n=58	12.1±7.9, 1-29, n=54	10.6±8.0, 1-30, n=38
A-PRI (range 0-12)	2.5±3.0, 0-12, n=58	3.6±3.2, 0-12, n=54	3.9±4.1, 0-12, n=38
Total PRI (range 0-45)	9.1±7.0, 1-29, n=58	15.3±9.9, 1-37, n=54	13.9±11.1, 1-39, n=38
Current LBP intensity	37.7±25.8 0-97, n=51	43.6±27.7 0-92, n=44	50.2±32.8 0-100, n=27
Intensity of LBP over last 1 month	40.9±26.8 0-98, n=51	51.6±24.8 0-95, n=44	51.1±30.0 0-92, n=27
Intensity of LBP over last 3 months	40.6±27.8 0-95, n=51	50.9±22.3 5-97, n=44	57.4±29.0 0-100[1], n=25

People with a thoracic injury reported significantly higher mean sensory PRI than people with a cervical injury (I-J=-4.62, p=0.003, Bonferroni post hoc). People with thoracic injury also reported significantly higher total PRI than people with cervical injuries (I-J=-6.19, p=0.002, Bonferroni post hoc). People with lumbar level injuries had significantly higher total PRI than people with cervical injuries (I-J=4.85, p=0.04, Bonferroni post hoc). No differences were found in the level of injury and affective PRI.

People with lumbar injuries seemed to report higher mean intneisty, in most of the cases. A significant difference was found between people with lumbar injury and people with cervical injury (I-J=-16.79, p=0.02, Bonferroni post hoc).

[1]missing two;[2]2 outliers eliminated, [3]3 outliers eliminated.

Abbreviations: PRI, Pain Rating Index; S-PRI, Sensory PRI; A-PRI, Affective PRI; NRS, Numeric Rating Scale; LBP, Low Back Pain, SD, Standard Deviation.

Table 6.5.5: Evaluative overall intensity of LBP in groups divided by level of injury and between group differences

	Cervical mean±SD, min-max	**Thoracic** mean±SD, min-max	**Lumbar** mean±SD, min-max	**Statistical test**
Evaluative PPI for LBP	2.2±1.0 1-5 n=58	2.3±0.8 1-4 n=52	2.4±1.0 0-4 n=33	H =0.81, df2 p=0.44

People with injuries at any level reported very similar their evaluative overall intensity of LBP and not significant differences were found (F=0.81, p=0.44, One way ANOVA).
Abbreviations: PPI, Present Pain Intensity; LBP, Low Back Pain.
Statistical Test: One way ANOVA.

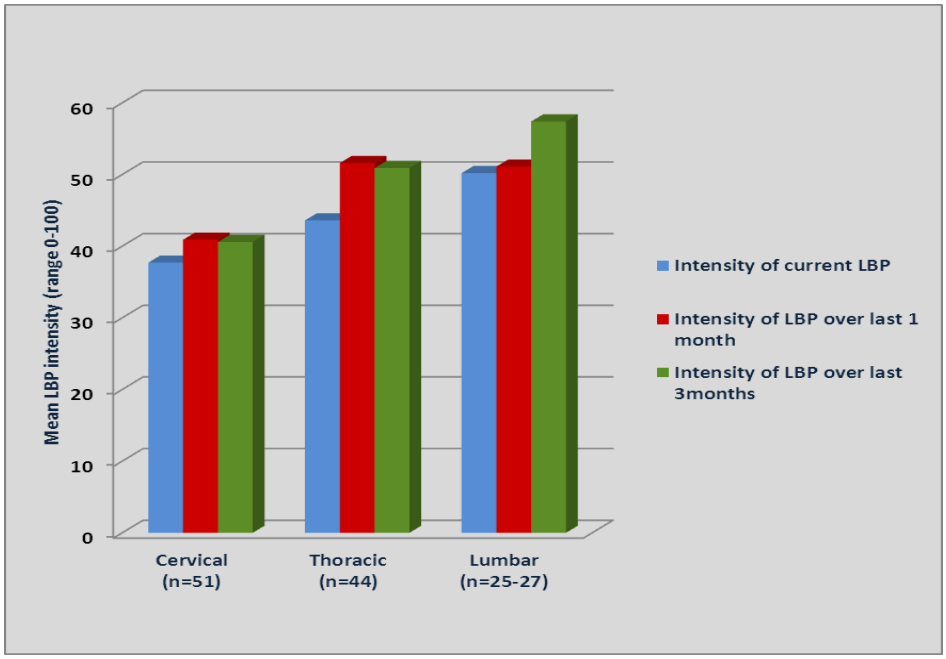

Figure 6.5.7: Mean LBP quality in groups divided by level of injury.
Abbreviations: PRI, Present Rating Index; S-PRI, Sensory PRI; A-PRI, Affective PRI; LBP, Low Back Pain

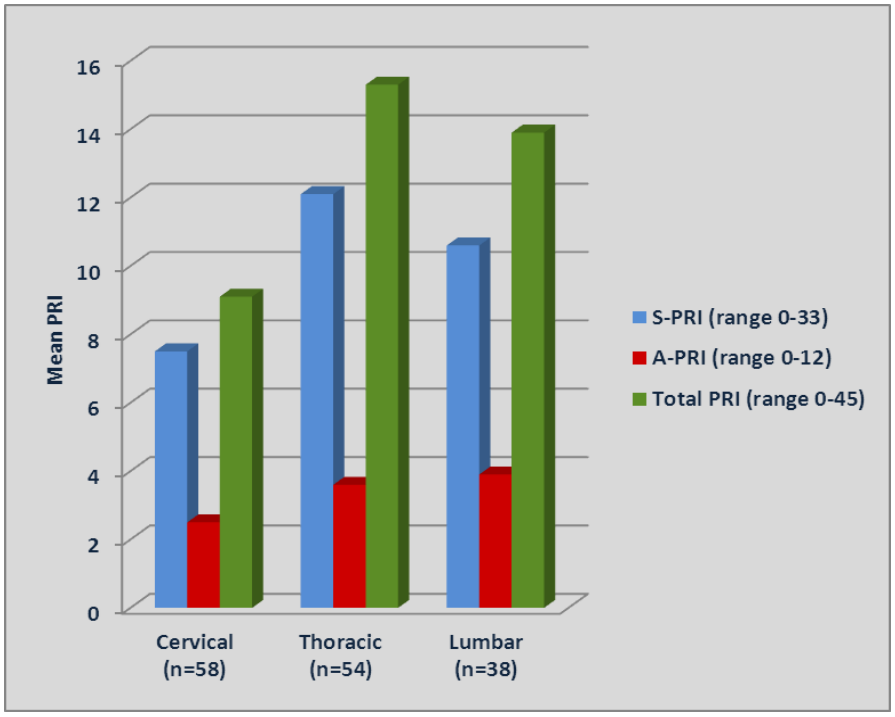

Figure 6.5.8: Mean LBP intensity in groups divided by level of injury.
Abbreviations: LBP, Low Back Pain; NRS, Numeric Rating Scale.

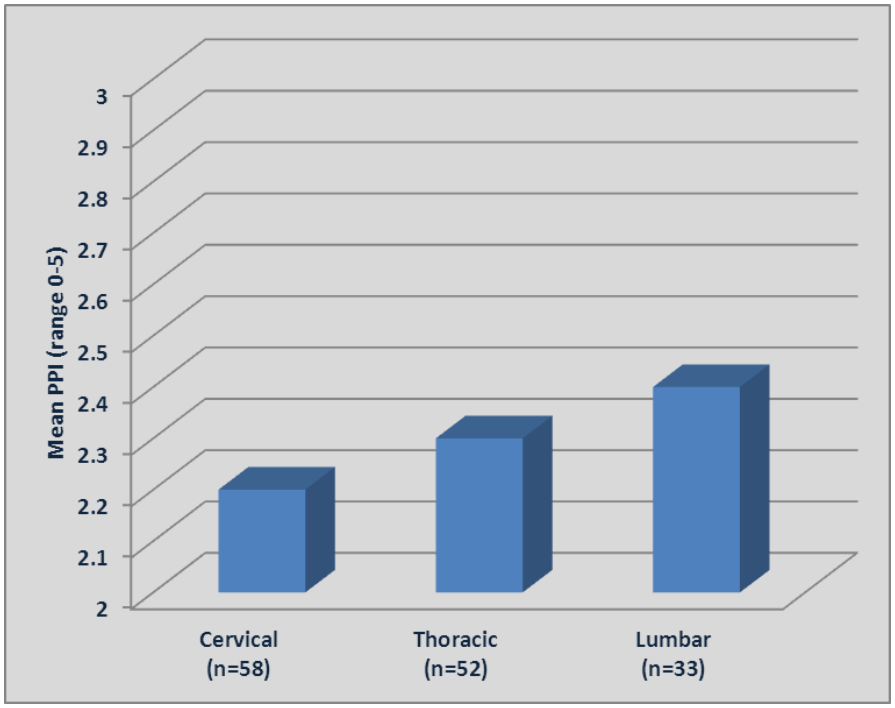

Figure 6.5.9: Mean LBP evaluative overall intensity in groups by level of injury.
Abbreviations: PPI, Present Pain Intensity; LBP, Low Back Pain.

6.6: LBP quality and intensity; relation with pain/LBP days, free period, onset

Table 6.6.1: Correlations between pain days, pain free weeks and pain onset with LBP quality and intensity

	Correlation between number of pain days and LBP quality and intensity	Correlation between pain free weeks and LBP quality and intensity	Correlation between pain onset post iSCI and LBP quality and intensity
S-PRI (range 0-33)	ρ=0.14 p=0.07, n=152	ρ=0.25 **p=0.002**** n=143	ρ=-0.13 p=0.10, n=152, 95%CI -0.16, 0.14
A-PRI (range 0-12)	ρ=0.07 p=0.33, n=152	ρ=0.23 **p=0.004**** n=143	ρ=-0.06 p=0.39, n=152 95%CI -0.21, 0.09
Total PRI (range 0-45)	ρ=0.11 p=0.17, n=149	ρ=0.23 **p=0.004**** n=140	ρ=-0.14 p=0.07, n=149 95%CI -0.29, 0.01
Intensity of current LBP	ρ=0.29 p≤0.01[1] n=124	ρ=0.42 **p≤0.001***** n=116	ρ=0.08 p=0.35, n=124 95%CI -0.09, 0.25
Intensity of LBP over 1 month	ρ=0.25 p=0.004[1] n=122	ρ=0.35 **p≤0.001***** n=114	ρ=0.08 p=0.33, n=122 95%CI -0.09, 0.25
Intensity of LBP 3 months	ρ=0.20 p=0.02[1] n=121	ρ=0.36 **p≤0.001***** n=113	ρ=0.08 p=0.34, n=121 95%CI -0.09, 0.25
Evaluative PPI of LBP	ρ=0.14 p=0.09, n=141	ρ=0.22 p≤0.01[1] n=132	ρ=-0.10 p=0.23, n=141 95%CI -0.25, 0.05

[1]not significant post Bonferroni correction; **Significant at p≤0.01 level, ***Significant at p≤0.001 level;
in bold: significant following application of the Bonferroni correction.
Abbreviations: PRI, Pain Rating Index; S-PRI, Sensory PRI; A-PRI, Affective PRI; PPI, Present Pain Intensity; LBP, Low Back Pain; NRS, Numeric Rating Scale.
Statistical test: ρ, Spearman's rank correlation rho

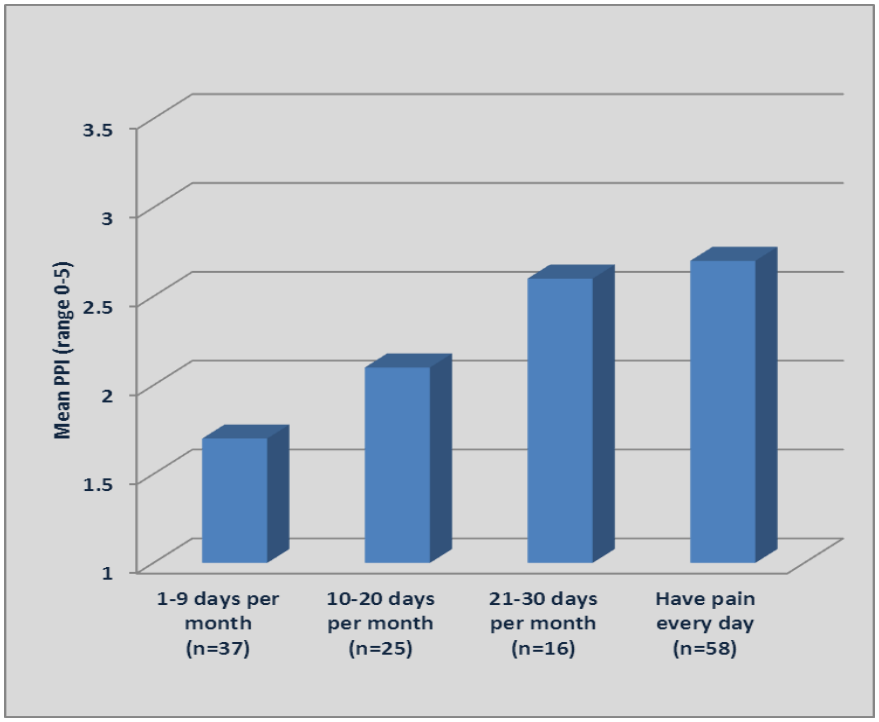

Figure 6.6.1: Mean evaluative overall PPI for LBP by number of LBP Days felt in a month.
Abbreviations: PPI, Present Pain Intensity; LBP, Low Back Pain.

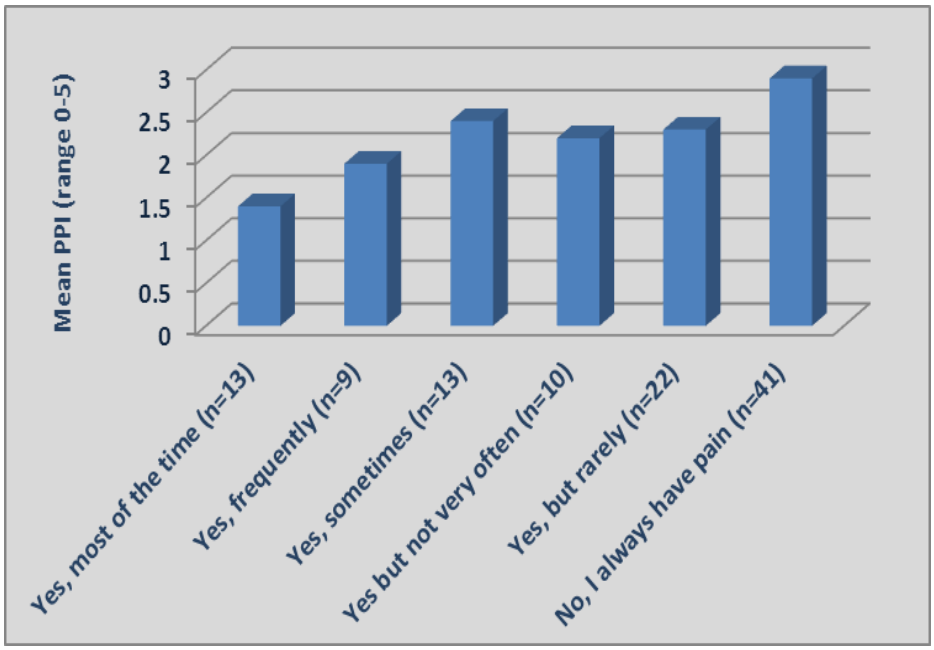

Figure 6.6.2: Mean evaluative overall PPI for LBP by gender.
Abbreviations: PPI, Present Pain Intensity; LBP, Low Back Pain.

Appendix 7; Quality of Life

Supplement to Chapter 7

7.1. Bonferroni Correction

Table 7.1.1: Main variables used in analysis of QoL and alpha value set following Bonferroni correction

Main Variable	Tests with following variables		Alpha value following Bonferroni correction
EQ-5D index and EQ-VAS	1) With pain	11) With employment	0.05/21=0.002 p≤0.002
	2) With MSKP	12) With pain days	
	3) With LBP (current)	13) With LBP days	
	4) With gender	14) With pain free weeks	
	5) With cause of injury	15) With LBP free weeks	
	6) With age	16) With pain onset	
	7) With type of injury	17) With LBP onset	
	8) With time since injury	18) With areas with pain	
	9) With education	19) With S-PRI	
	10) With marital status	20) With A-PRI	
		21) With total PRI	

Abbreviations: EQ-5D index, Quality of Life index; EQ-VAS, Quality of Life Visual Analogue Scale; MSKP, Musculoskeletal Pain; LBP, Low Back Pain; PRI, Present Rating Index; S-PRI, Sensory PRI; A-PRI, Affective PRI

7.2: QoL; general results

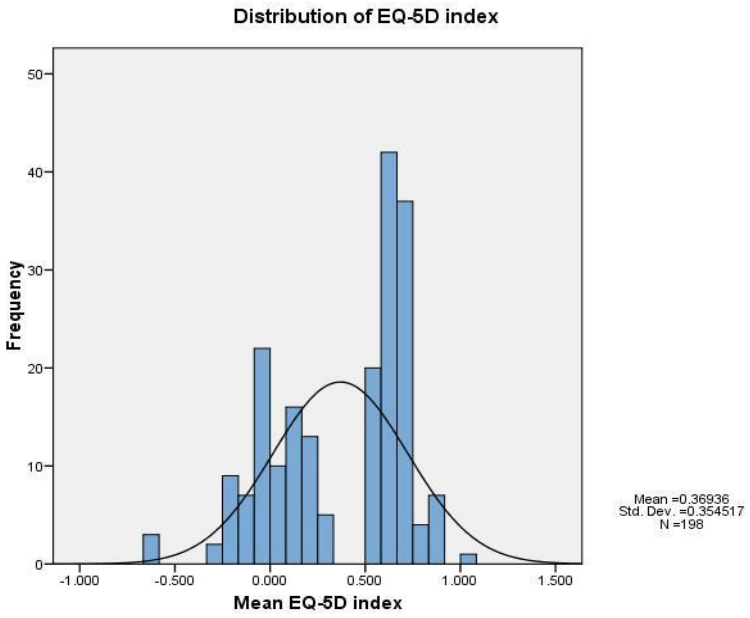

Figure 7.2.1: Bimodal distribution of EQ-5D Index (n=198). Abbreviations: EQ-5D index, Quality of Life index.

Table 7.2.1: Frequency distribution of all the 64 reported health profiles with mean index and EQ-VAS values

Rank order	EQ-5D profile	Count	%	Mean index value (UK TTO)	Mean EQ-VAS	Range of mean EQ-VAS
1	11111	1	0.5	1.000	90.0	90
2	11211	2	1.0	0.883	72.5	70-75
3	21111	4	**2.0**	0.850	89.7	70-99
4	11112	1	0.5	0.848	60.0	60
5	21211	1	0.5	0.814	80.0	80
6	11121	2	1.0	0.796	88.5	80-95
7	11221	1	0.5	0.760	75.0	75
8	22111	3	1.5	0.746	96.0	95-98
9	21212	2	1.0	0.743	60.0	50-70
10	21121	8	**4.0**	0.727	85.4	80-95
11	11122	2	1.0	0.725	54.5	40-69
12	22211	3	1.5	0.710	73.3	65-85
13	21221	16	**8.1**	0.691	72.0	29-90
14	11222	3	1.5	0.689	69.3	58-90
15	21122	6	**3.0**	0.656	74.6	49.5-100
16	22212	5	**2.5**	0.639	59.0	50-85
17	21222	20	**10.0**	0.620	67.6	40-95
18	22221	10	**5.1**	0.587	58.0	20-90
19	22222	20	**10.1**	0.516	56.1	40-80
20	23211	2	1.0	0.331	90.0	90
21	23311	1	0.5	0.273	100	100
22	22321	2	1.0	0.260	41.5	33-50
23	23221	1	0.5	0.208	90.0	90
24	22213	1	0.5	0.205	38.0	38
25	32211	1	0.5	0.196	95.0	95
26	21131	3	1.5	0.195	88.3	80-100
27	11132	1	0.5	0.193	90.0	90
28	22322	4	**2.0**	0.189	48.0	35-62
29	21223	1	0.5	0.186	50.0	50
30	31221	1	0.5	0.177	80.0	80
31	21231	3	1.5	0.159	73.3	40-98
32	23321	2	1.0	0.150	80.0	75-85
33	31122	2	1.0	0.142	70.0	60-80
34	23222	2	1.0	0.137	82.5	70-95
35	32212	1	0.5	0.125	30.0	30
36	22123	1	0.5	0.118	77.0	77
37	32121	1	0.5	0.109	88.0	88
38	21232	4	**2.0**	0.088	55.0	35-80
39	22223	3	1.5	0.082	49.3	30-40

The table is ranked in order of decreasing health according to the mean health index value; **in bold** are the 12 most frequently reported health profiles.
Abbreviations: EQ-5D, Quality of Life.

Table 7.2.1 continued: Frequency distribution of all the 64 reported health profiles with mean index and EQ-VAS values

Rank order	EQ-5D profile	Count	%	Mean index value (UK TTO)	Mean EQ-VAS	Range of mean EQ-VAS
40	32221	1	0.5	0.073	70.0	70
41	22231	1	0.5	0.055	50.0	50
42	33311	1	0.5	0.028	70.0	70
43	32321	2	1.0	0.015	45.0	10-80
44	32222	2	1.0	0.002	34.5	34-35
45	22331	1	0.5	-0.003	70.0	70
46	11233	1	0.5	-0.008	50.0	50
47	22232	6	**3.0**	-0.016	40.0	20-60
48	33221	1	0.5	-0.037	80.0	80
49	21133	1	0.5	-0.041	32.0	32
50	23231	1	0.5	-0.055	70.0	70
51	32322	2	1.0	-0.056	42.5	40-45
52	22332	6	**3.0**	-0.074	35.7	5-65
53	21233	3	1.5	-0.077	65.0	40-80
54	33321	2	1.0	-0.095	82.5	80-85
55	33222	3	1.5	-0.108	56.7	30-90
56	33322	2	1.0	-0.166	50.0	30-70
57	22233	4	2.0	-0.181	32.5	0-50
58	23332	1	0.5	-0.184	40.0	40
59	31332	1	0.5	-0.215	35.0	35
60	32323	1	0.5	-0.221	30.0	30
61	22333	2	1.0	-0.239	34.0	28-40
62	32232	1	0.5	-0.261	80.0	80
63	33323	1	0.5	-0.331	70.0	70
64	33333	3	1.5	-0.594	14.0	10-22

The table is ranked in order of decreasing health according to the mean health index value; **in bold** are the 12 most frequently reported health profiles.
Abbreviations: EQ-5D, Quality of Life.

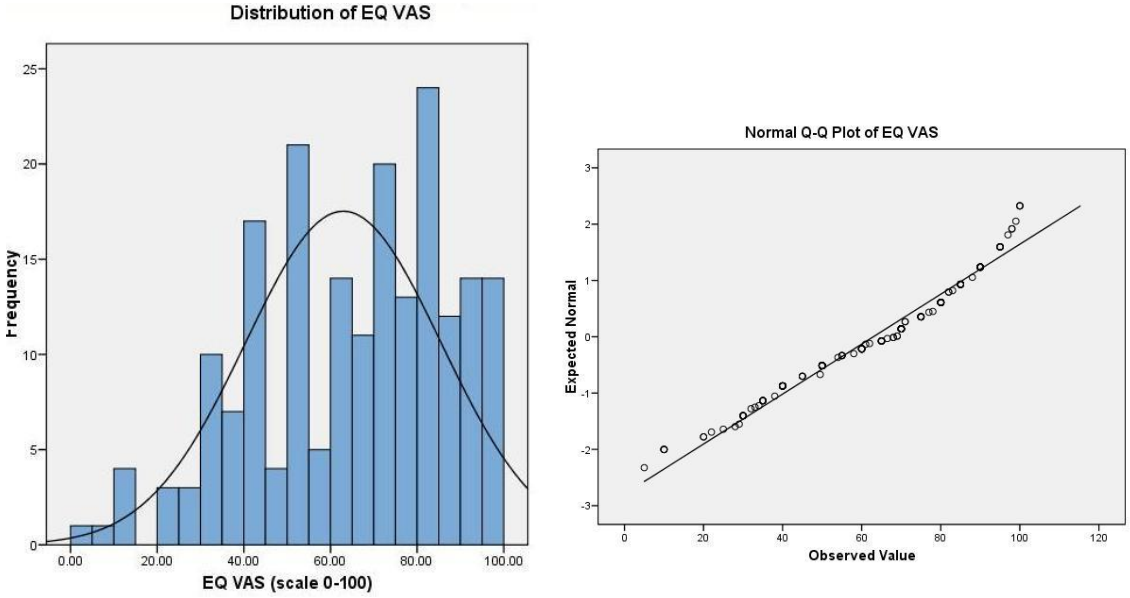

Figure 7.2: Histogram with normal curve and Q-Q plot for the EQ-VAS
Abbreviations: EQ-VAS, Quality of Life Visual Analogue Scale.

7.3: QoL; relation to demographic profiles

Table 7.3.1: Percentage of people reporting on health status dimensions divided into groups by gender, cause and level of injury

		Total group % n=198	Gender[1] %		Cause of injury %		Level of injury %	
			Male n=120	Female n=75	Traumatic n=139	Non traumatic n=59	Tetraplegia n=91	Paraplegia n=66
Mobility	Level 1	7.1	9.2	2.7	8.6	3.4	7.7	6.5
	Level 2	78.3	78.3	80.0	77.7	79.7	72.5	83.2
	Level 3	14.6	12.3	17.3	13.7	16.9	19.8	10.3
Self-Care	Level 1	45.5	45	46.7	47.5	40.7	33	56.1
	Level 2	42.9	42.5	42.7	38.8	52.5	44	42.1
	Level 3	11.6	12.5	10.7	13.7	6.8	23.1	1.9
Usual Activities	Level 1	18.7	20.8	14.7	20.9	13.6	18.7	18.7
	Level 2	64.1	65.8	61.3	63.3	66.1	59.3	68.2
	Level 3	17.2	13.3	24	15.8	20.3	22	13.1
Pain / Discomfort	Level 1	14.6	15.8	12	16.5	10.2	20.9	9.3
	Level 2	63.6	65	62.7	64	62.7	62.6	64.5
	Level 3	21.7	19.2	25.3	19.4	27.1	16.5	26.2
Anxiety / Depression	Level 1	39.9	45.8	32	48	20.3	50.7	30.8
	Level 2	49	43.3	57.3	42.4	64.4	39.6	57.0
	Level 3	11.1	10.8	10.7	9.4	15.3	9.9	12.1

[1]3 respondents did not give their gender

Table 7.3.2: EQ-5D index and EQ-VAS reported by males and females. Statistical difference of EQ-5D index and EQ-VAS between gender

		Male	Female	Statistical Tests
EQ-5D Index	n	120	75	p=0.18
	Mean±SD	0.4±0.3	0.3±0.3	t=1.48[1], df193
	Median	0.5	0.5	95% CI -0.02, 0.1
	Percentile 25th	0.1	-0.01	U=3889.0, p=0.1
	Percentile 75th	0.7	0.6	
EQ-VAS	n	120	75	p=0.50
	Mean±SD	64.0±23.9	61.7±20.3	t=0.67, df193
	Median	70	65	95% CI -4.33, 8.79
	Percentile 25th	50	45	
	Percentile 75th	85	80	

[1]Independent t-test could be used in this case because despite data being bimodal it was rather symmetric (mean and median approximately equal) therefore filling the assumptions for t-test.{{682 Peacock, J. 2007}}

Abbreviations: EQ-5D, Quality of Life; EQ-VAS, Quality of Life Visual Analogue Scale SD, Standard Deviation.

Statistical tests: t, Independent t-test; U, Mann-Whitney U test.

Table 7.3.3: EQ-5D index and EQ-VAS reported betwenn gender. Statistical difference between gender reports.

	With MSKP mean±SD, n	**Without MSKP** mean±SD, n	**Statistical Test**
		EQ-5D Index	
Males	0.4±0.3, n=39	0.4±0.3, n=79	p=0.37, df116, t=0.88 95% CI -0.07, 0.19, ES d=0.28
Females	0.2±0.3, n=36	0.4±0.3, n=37	p=0.06, df71, t=1.90 95% CI -0.006, 0.31, ES d=0.66
		EQ-VAS	
Males	61.9±23.0, n=39	64.6±24.6, n=79	p=0.56, df116, t=0.57 95% CI -6.6, -12.5, ES d=0.11
Females	52.9±17.7, n=36	69.9±19.4, n=37	**p≤0.001*****, df71, t=3.89 95% CI 8.3, 25.7, ES d=0.91

In bold: significant following application of the Bonferroni correction.

The only significant difference found was among females as those without MSKP had a better self-rated health that those with MSKP and the effect size was larger than typical.

Abbreviations: MSKP, Musculoskeletal pain, EQ-5D, Quality of Life, EQ-VAS, Quality of life Visual Analogue Scale.

Table 7.3.4: EQ-5Q index and EQ-VAS for people with traumatic and non-traumatic injury. Statistical difference of EQ-5D and EQ-VAS between groups by cause of injury

		Traumatic	Non-traumatic	Statistical Test
EQ-5D Index	n	139	59	U=3441.5
	Mean±SD	0.4±0.3	0.3±0.4	p=0.07
	Median	0.5	0.5	
	Percentile 25th	0.08	-0.04	
	Percentile 75th	0.69	0.6	
	Skewness	-0.05	-0.5	
	Kyrtosis	-0.07	-1.1	
EQ-VAS	n	139	59	t=-2.85, df49
	Mean±SD	66.8±22.7	53.8±19.5	p=0.006[1]
	Median	71	50	95% CI -43.0,
	Percentile 25th	50	40	-7.5
	Percentile 75th	85	69	
	Skewness	-0.8	0.008	
	Kyrtosis	-0.1	-0.3	

[1]not significant post Bonferroni correction

Abbreviations: EQ-5D, Quality of Life; SD, EQ-VAS, Quality of Life Visual Analogue Scale Standard Deviation.

Statistical test: U, Mann-Whitney U test; t, Independent t-test

Table 7.3.5: EQ-5D index and EQ-VAS for people with tetraplegia and paraplegia. Differences in EQ-5D and EQ-VAS between groups divided by level of injury

		Tetraplegia	Paraplegia	Statistical Test
EQ-5D Index	n	91	107	U=4772
	Mean±SD	0.3±0.4	0.3±0.4	p=0.81
	Median	0.3	0.3	
	Percentile 25th	-0.01	0.01	
	Percentile 75th	0.7	0.7	
	Skewness	-0.5	-0.5	
	Kurtosis	-0.7	-0.7	
EQ-VAS	n	91	107	t=2.41, df196
	Mean±SD	67.1±23.9	59.4±20.8	p≤0.01[1]
	Median	70	60	95% CI 1.4, 13.9
	Percentile 25th	50	40	
	Percentile 75th	85	80	
	Skewness	-0.8	-0.2	
	Kurtosis	0.03	-0.7	

[1]Not siginifcant post application of the Bonferroni correction.

Abbreviations: EQ-5D, Quality of Life; SD, EQ-VAS, Quality of Life Visual Analogue Scale Standard Deviation.

Statistical test: U, Mann-Whitney U test; t, Independent t-test

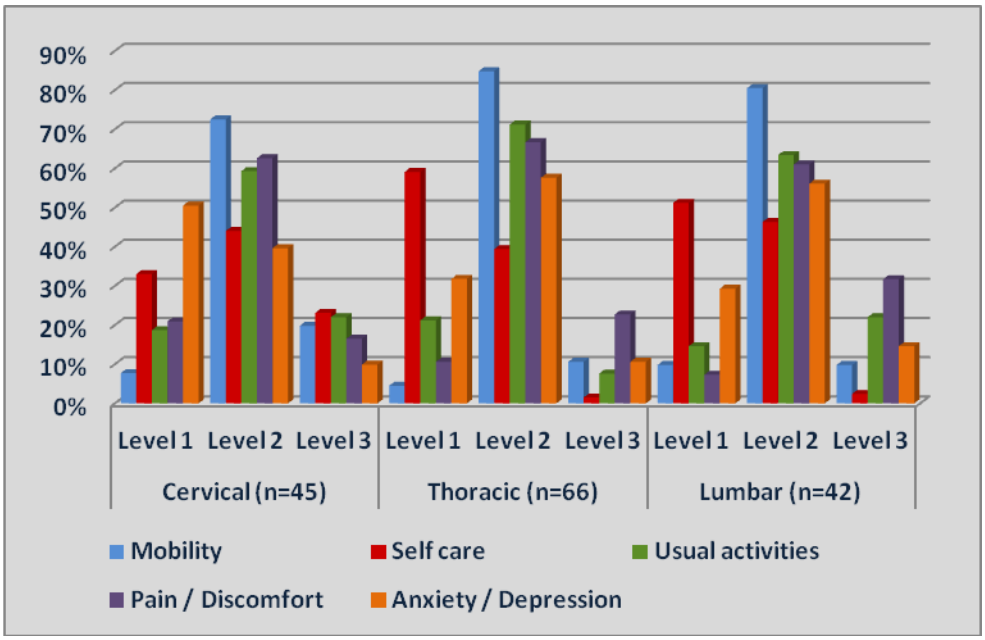

Figure 7.3.1: Percentage of people, divided into groups by level of injury, reporting each health status dimension.
Abbreviations: EQ-5D, Quality of Life

Table 7.3.6: Characteristics of EQ-5D index and EQ-VAS per level of injury. Differences inEQ-5D and EQ-VAS between groups.

		Cervical	Thoracic	Lumbar	Statistical Test
EQ-5D Index	n	95	66	42	p=0.47
	Mean±SD	0.3±0.4	0.4±0.3	0.3±0.4	H=1.5, df2
	Median	0.3	0.6	0.5	
	Percentile 25th	-0.008	0.1	-0.1	
	Percentile 75th	0.7	0.6	0.7	
	Skewness	-0.3	-0.8	-0.2	
	Kurtosis	-0.8	-0.6	-1.5	
EQ-VAS	n	91	66	41	p=0.015[1]
	Mean±SD	67.1±23.9	62.2±19.8	55.0±22.8	F=4.28, df2
	Median	70	65	50	
	Percentile 25th	50	50	40	
	Percentile 75th	85	80	73	
	Skewness	-0.8	-0.3	-0.1	
	Kurtosis	0.01	-0.5	-0.9	

[1]Not siginifcant post application of the Bonferroni correction.
Abbreviations: EQ-5D, Quality of Life; SD, Standard Deviation; EQ-VAS, Quality of Life Visual Analogue Scale
Statistical Test: H, Kruskal-Wallis H; F, One-way ANOVA

Table 7.3.7: Two group comparisons for EQ-VAS between groups divided by level of injury

	Cervical	Thoracic
Thoracic	I-J= 4.9 p=0.36	
Lumbar	I-J= 12.1 **p≤0.01****	I-J= 7.2 p=0.23

**Significant at 0.01 level;
in bold: significant following Bonferroni post hock
Abbreviations: EQ-VAS, Quality of Life Visual Analogue Scale.

Table 7.3.8: Percentage of people reporting the EQ-5D dimensions divided in groups by age and time since injury

		Age n=190[1]					Time Since Injury n=197[2]				
		n	Mean	SD	Median	Min - Max	n	Mean	SD	Median	Min - Max
Mobility	Level 1	12	48.9	13.2	48.2	33.4 - 70.6	14	7.0	5.1	6.0	0.6 – 19.4
	Level 2	150	50.9	14.2	51.3	19.8 – 91.7	155	11.8	10.9	8.1	0.3 – 44.0
	Level 3	28	46.0	15.8	43.7	23.0 – 90	29	12.3	11.7	8.1	0.3 – 44.2
Self-Care	Level 1	86	48.5	14.6	49.1	19.8 – 83.8	90	11.6	10.8	7	0.4 – 44.0
	Level 2	82	52.1	13.7	53	26.6 – 91.7	85	11.4	11.2	8.5	0.3 – 44.2
	Level 3	22	48.3	16.0	44.6	23.4 – 90	23	11.5	9.3	8.0	1.1 – 29.2
Usual Activities	Level 1	33	47.6	13.5	49.2	23.0 – 70.6	37	14.6	10.9	11.8	1.0 – 41.7
	Level 2	125	50.3	14.8	50.9	19.8 – 91.7	127	11.2	11.2	7.2	0.3 – 44.2
	Level 3	33	51.4	13.9	50	23.4 – 90	34	9.3	9.0	6.1	0.3 – 30.8
Pain / Discomfort	Level 1	26	46.7	15.0	41.9	26.6 – 79.9	29	10.1	9.6	8.9	0.9 – 41.7
	Level 2	121	51.1	14.4	51.6	23.0 – 91.7	126	11.2	11.0	6.8	0.3 – 44.2
	Level 3	43	49.1	14.2	48.7	19.8 – 89.1	43	13.2	10.8	9.1	0.5 – 43.2
Anxiety / Depression	Level 1	71	47.8	12.3	49.4	26.6 – 83.8	79	13.5	12.3	8.7	0.4 – 44.0
	Level 2	97	51.4	15.7	50.9	23.0 – 91.7	97	10.1	9.5	7.6	0.3 – 44.2
	Level 3	22	50.7	14.8	48.7	19.8 – 76.5	22	10.7	9.6	7.5	0.6 – 34.3

[1]n=8 did not report their age, [2]n=1 did not report their time since injury

Table 7.3.9: Percentage of people, divided into groups by level of education, reporting the health status dimensions

		No education or compulsory	High school	College, Associate or Bachelor Degree	Master of PhD
Mobility	Level 1	4.5	9.1	6.3	8.8
	Level 2	81.8	77.3	77.1	79.4
	Level 3	13.6	13.6	16.7	11.8
Self-Care	Level 1	36.4	45.5	45.8	50
	Level 2	54.5	36.4	43.8	41.2
	Level 3	9.1	18.2	10.4	8.8
Usual Activities	Level 1	9.1	15.9	21.9	17.6
	Level 2	77.3	59.1	36.5	64.7
	Level 3	13.6	25	14.6	17.6
Pain / Discomfort	Level 1	18.2	9.1	17.7	11.8
	Level 2	59.1	59.1	64.6	70.6
	Level 3	22.7	31.8	17.7	17.6
Anxiety / Depression	Level 1	27.3	38.6	40.6	47.1
	Level 2	54.5	50	49	47.1
	Level 3	18.2	11.4	10.4	5.9

7.4: QoL; relation to pain/LBP days, free periods, onset

Table 7.4.1: Number of pain and LBP days felt in a month and EQ-VAS

		1-9 days	10 – 20 days	21 – 30 days	Every day	Statistical Test
EQ-5D Index	Pain days					
	n	27[1]	26	18	105	**p≤0.001*** **
	Mean±SD	0.5±0.3	0.4±0.3	0.2±0.3	0.3±0.3	ρ=-0.24
	Median	0.7	0.6	0.2	0.2	n=176
	Percentile 25th	0.6	0.1	0.1	-0.01	
	Percentile 75th	0.7	0.7	0.6	0.6	
	Skewness	-1.6	-0.7	-0.7	-0.3	
	Kurtosis	1.2	-1.2	0.1	-1.0	
EQ-5D Index	LBP days					
	n	39[1]	27	18	64	**p≤0.001*** **
	Mean±SD	0.4±0.4	0.4±0.3	0.2±0.3	0.2±0.3	ρ=-0.24
	Median	0.6	0.6	0.1	0.2	n=148
	Percentile 25th	0.1	0.2	-0.1	-0.1	
	Percentile 75th	0.7	0.7	0.5	0.6	
	Skewness					
	Kurtosis					
EQ-VAS	Pain days					
	n	28	26	18	105	p=0.03[2]
	Mean±SD	70.5±17.9	66.4±23.0	60.9±22.9	59.9±23.4	ρ=-0.16
	Median	70	72.5	60	60	n=177
	Percentile 25th	58.5	43.7	40	40	
	Percentile 75th	88.7	83.7	80	80	
	Skewness	-0.1	-0.5	-0.1	-0.5	
	Kurtosis	-0.7	-1.5	-1.4	-0.5	
EQ-VAS	LBP days					
	n	36	27	18	58	p=0.003[2]
	Mean±SD	68.8±19.6	63.5±22.0	54.5±19.1	54.2±24.2	ρ=-0.35
	Median	70	66.5	50	57.5	n=139
	Percentile 25th	52	40	40	38.7	
	Percentile 75th	85	80	72	75	
	Skewness	-0.6	-0.5	-0.1	-0.5	
	Kurtosis	-0.4	-1.0	-1.4	-0.5	

[1]One outlier eliminated from analysis; [2]not significant post application of the Bonferroni correction; ***significant at p≤0.01 level; **in bold:** significant following Bonferroni correction
Abbreviations: EQ-5D, Quality of Life ; EQ-VAS, Quality of Life Visual Analogue Scale; SD, Standard Deviation.
Statistical Test: ρ, Spearman's rho.

Table 7.4.2: Percentage of people reporting the health status dimensions divided into groups by frequency of pain and LBP free weeks

		1 week pain free week % n=167 [1]						1 week LBP free week % n=122 [1]					
		Yes, most of time	Yes, frequently	Yes, some times	Yes, not often	Yes, rarely	No, always have pain	Yes, most of time	Yes, frequently	Yes, some times	Yes, not often	Yes, rarely	No, always have pain
Mobility	Level 1	13.3	11.8	0	0	5.3	7.1	12.5	11.1	7.1	0	4.2	8.5
	Level 2	73.3	70.6	77.8	92.3	78.9	81.2	81.3	77.8	71.4	100	83.3	76.6
	Level 3	13.3	17.6	22.2	7.7	15.8	11.8	6.3	11.1	21.4	0	12.5	14.9
Self-Care	Level 1	46.7	58.8	33.3	69.2	63.2	38.3	58.8	66.7	42.9	54.5	58.3	29.2
	Level 2	40.0	41.2	50	23.1	21.1	48.2	35.3	33.3	35.7	45.5	33.3	58.3
	Level 3	13.3	0	16.7	7.7	15.8	12.9	5.9	0	21.4	0	8.3	12.5
Usual Activities	Level 1	40.0	29.4	5.6	30.8	31.6	10.6	29.4	22.2	21.4	27.3	16.7	8.3
	Level 2	53.3	70.6	77.8	61.5	47.4	64.7	64.7	77.8	42.9	54.5	70.8	62.5
	Level 3	6.7	0	16.7	7.7	21.1	24.7	5.9	0	35.7	18.2	12.5	29.2
Pain / Discomfort	Level 1	33.3	11.8	5.6	0	5.3	1.2	5.9	0	7.1	0	8.7	0
	Level 2	66.7	88.2	94.4	61.5	78.9	60.0	70.6	88.9	85.7	63.6	73.9	54.2
	Level 3	0	0	0	38.5	15.8	38.8	23.5	11.1	7.1	36.4	17.4	45.8
Anxiety / Depression	Level 1	46.7	29.4	38.9	30.8	31.6	40.0	31.3	44.4	35.7	36.4	45.8	29.2
	Level 2	46.7	58.8	55.6	53.8	57.9	45.9	68.8	55.6	50	45.5	41.7	52.1
	Level 3	6.7	11.8	5.6	15.4	10.5	14.1	0	0	14.3	18.2	12.5	18.8

[1] Including only people with pain/LBP and excluding those who did not remember when the onset of their pain/LBP post SCI was.
Abbreviations: EQ-5D, Quality of Life; LBP, Low Back Pain.

Table 7.4.3: EQ-5D index in groups divided by frequency of pain and LBP free weeks

Pain/LBP free weeks	EQ-5D index per groups of pain free weeks	EQ-5D index per groups of LBP free weeks
Yes, most of the time		
n	14[1]	14[1]
Mean±SD	0.6±0.3	0.5±0.2
Median	0.7	0.6
Percentile 25th	0.5	0.4
Percentile 75th	0.7	0.7
Skewness	-2.1	-1.3
Kurtosis	5.1	0.2
Yes frequently		
n	17	7[2]
Mean±SD	0.5±0.3	0.6±0.1
Median	0.6	0.7
Percentile 25th	0.2	0.5
Percentile 75th	0.7	0.7
Skewness	-0.9	-0.7
Kurtosis	-0.9	-1.4
Yes, sometimes		
n	18	14
Mean±SD	0.4±0.3	0.3±0.4
Median	0.5	0.5
Percentile 25th	0.1	-0.1
Percentile 75th	0.6	0.7
Skewness	-1.1	-0.4
Kurtosis	-0.3	-1.7
Yes, but not very often		
n	13	11
Mean±SD	0.3±0.4	0.3±0.4
Median	0.6	0.6
Percentile 25th	0.03	-0.04
Percentile 75th	0.7	0.6
Skewness	-0.3	-0.4
Kurtosis	-2.0	-1.9
Yes, but rarely		
n	19	21[1]
Mean±SD	0.4±0.4	0.5±0.3
Median	0.6	0.6
Percentile 25th	-0.07	0.2
Percentile 75th	0.7	0.7
Skewness	-1.0	-0.8
Kurtosis	0.3	-0.3
No, I always have pain		
n	85	45
Mean±SD	0.2±0.3	0.2±0.3
Median	0.2	0.2
Percentile 25th	-0.01	-0.1
Percentile 75th	0.6	0.5
Skewness	-0.1	0.05
Kurtosis	-1.0	-1.1

[1]One outlier eliminated, [2]Two outliers eliminated.

Abbreviations: EQ-5D, Quality of Life; SD, Standard Deviation; LBP, Low Back Pain.

Table 7.4.4: EQ-VAS in groups divided by regularity of pain and LBP free weeks

Pain/LBP free week		EQ-VAS for pain	EQ-VAS for LBP
Yes, most of the time			
	n	15	15
	Mean±SD	77.4±20.1	66.1±19.5
	Median	75	69
	Percentile 25th	62.2	40
	Percentile 75th	95	80
	Skewness	-0.5	-0.4
	Kurtosis	-0.8	-1.2
Yes frequently			
	n	17	9
	Mean±SD	64.3±16.6	63.7±15.9
	Median	60	70
	Percentile 25th	50	52.5
	Percentile 75th	77.75	75.5
	Skewness	0.1	-0.6
	Kurtosis	-0.3	0.007
Yes, sometimes			
	n	18	14
	Mean±SD	60.3±18.7	57.8±19.0
	Median	60.5	63.2
	Percentile 25th	42.5	40
	Percentile 75th	77.5	75.5
	Skewness	0.1	-0.2
	Kurtosis	-1.3	-1.6
Yes, but not very often			
	n	13	11
	Mean±SD	58.4±25.1	54.1±18.6
	Median	50	50
	Percentile 25th	31	40
	Percentile 75th	85	70
	Skewness	0.03	0.1
	Kurtosis	-1.6	-0.8
Yes, but rarely			
	n	18[1]	22
	Mean±SD	75.4±17.8	62.8±21.0
	Median	77.5	70.5
	Percentile 25th	70	47.5
	Percentile 75th	85	80
	Skewness	-1.6	-0.4
	Kurtosis	4.0	-1.0
No, I always have pain			
	n	85	45
	Mean±SD	58.4±25.0	51.2±24.0
	Median	62	50
	Percentile 25th	40	32.5
	Percentile 75th	80	72.5
	Skewness	-0.4	-0.1
	Kurtosis	-0.7	-0.9

[1]One outliers eliminated.

Abbreviations: EQ-VAS, Quality of Life Visual Analogue Scale; SD, Standard Deviation.

7.5 EQ-5D; relation to pain extent

Table 7.5.1: Percentage of people reporting each EQ-5D dimension divided in groups by pain presence and number of days in pain

		% of number of pain days per month n=177[1]				% of number of LBP days per month n=139[1]			
		1-9	**10-20**	**21-30**	**Everyday**	**1-9**	**10-20**	**21-30**	**Everyday**
Mobility	Level 1	7.1	11.5	0	5.5	5.6	11.1	0	6.9
	Level 2	78.6	65.4	83.3	81.9	83.3	77.8	77.8	81
	Level 3	14.3	23.1	16.7	12.4	11.1	11.1	22.2	12.1
Self-Care	Level 1	60.7	50	55.6	41.0	55.6	55.6	44.4	37.9
	Level 2	32.1	34.6	33.3	48.6	30.6	40.7	50	55.2
	Level 3	7.1	15.4	11.1	10.5	13.9	3.7	5.6	6.9
Usual Activities	Level 1	35.7	15.4	22.2	14.3	25.0	25.9	22.2	6.9
	Level 2	57.1	73.1	72.2	61.0	66.7	66.7	55.6	67.2
	Level 3	7.1	11.5	5.6	24.8	8.3	7.4	22.2	25.9
Pain / Discomfort	Level 1	25	7.7	0	0	11.1	11.1	0	0
	Level 2	71.4	88.5	61.1	67.6	77.8	74.1	61.1	65.5
	Level 3	3.6	3.8	38.9	32.4	11.1	14.8	38.9	34.5
Anxiety / Depression	Level 1	50	34.6	22.2	38.1	47.2	33.3	27.8	34.5
	Level 2	42.9	53.8	55.6	50.5	44.4	59.3	61.1	48.3
	Level 3	7.1	11.5	22.2	11.4	8.3	7.4	11.1	17.2

[1] Including only people with pain/LBP and excluding those who did not recall when the onset of their pain/LBP was.

Abbreviations: EQ-5D, Quality of Life; LBP, Low Back Pain; MSKP, Musculoskeletal Pain.

Appendix 8; Function

Supplement for Chapter 8

8.1. Bonferroni correction

Table 8.1.1: Main variables used in analysis of function and alpha value set following Bonferroni correction.

Main Variables	Tests with following variables		Alpha value following Bonferroni correction
Self-care, Respiration & Sphincter management, Mobility in room & toilet, Mobility indoor & outdoor, Total SCIM	1) Pain 2) MSKP 3) LBP (current) 4) Gender 5) Cause of injury 6) Age 7) Type of injury 8) Time since injury 9) Current LBP intensity 10) LBP intensity 1 month 11) EQ-5D index 12) EQ-VAS	13) LBP intensity 3 months 14) With pain days 15) With LBP days 16) With pain free weeks 17) With LBP free weeks 18) With pain onset 19) With LBP onset 20) With areas with pain 21) With S-PRI 22) With A-PRI 23) With total PRI	0.05/23=0.002 p≤0.002

Abbreviations: EQ-5D index, Quality of Life index; EQ-VAS, Quality of Life Visual Analogue Scale; MSKP, Musculoskeletal Pain; LBP, Low Back Pain; PRI, Present Rating Index; S-PRI, Sensory PRI; A-PRI, Affective PRI

8.2. Translation

Table 8.2.1: Characteristics of forward translators

Occupations	n=2 Occupational Therapists n=1 Physiotherapist	
Years living in the UK		6.8±2.0 (mean±SD)
Hours to translate questionnaire		2.5±0.4 (mean±SD)
Use of dictionary	n=2 "Yes, but rarely" n=1 "Yes, frequently"	
Overall difficulty to translate[1]		4.3±3.0[1] (mean±SD)
Easiest question to translate[1]	Question 17	1.0±1.0[1] (mean±SD)
The most difficult question to translate[1]	Question 7	6.3±2.9[1] (mean±SD)

[1]0-10 NRS (0=very easy -10=the most difficult translation)-two translators failed to respond.
Abbreviation: NRS, Numeric Rating Scale

8.3. GR-SCIM III; relation to demographic profile characteristics

Table 8.3.1: Mean function scores and statistical differences in function between males and females

	Males n=23 mean±SD, median, min-max	**Females** n=18 mean±SD, median, min-max	**Statistical Tests**
Self-care subscale (range 0-20)	13.1±5.4 15, 2-20	16.0±4.8 18, 6-20	U=137.5 p=0.065 n=41
Respiration & sphincter management (range 0-40)	33.2±7.6 36, 11-40	35.2±8.1 38.5, 15-40	U=153.0 p=0.15 n=41
Mobility room & toilet (range 0-10)	8.3±2.6 10, 0-10	8.1±2.4 10, 4-10	U=193.0 p=0.67 n=41
Mobility indoor & outdoor (range 0-30)	18.6±10.0 23, 1-30	19.1±10.1 20, 0-30	U=195.0 p=0.75 n=41
Total SCIM (range 0-100)	73.2±21.6 81, 34-95	78.3±22.6 83.50, 28-100	U=158.5 p=0.20 n=41

Abbreviation: SD, Standard Deviation;
Statistical test: t, Independent t-test; U, Mann-Whitney U test.

Table 8.3.2: Mean function scores, within gender, for people with and without MSKP. Differences within males and females

Males with MSKP n, mean±SD	**Males without MSKP** n,mean±SD	**Females with MSKP** n, mean±SD	**Females without MSKP** n, mean±SD
n=6 68.8±28.9 15, 2-20	n=6 68.8±28.9 15, 2-20	n=6 68.8±28.9 15, 2-20	n=6 68.8±28.9 15, 2-20
Statistical test U= 41.0, p=0.75,		**Statistical test** U=32.5, p=0.73,	

Abbreviation: SD, Standard Deviation; MSKP, Muskuloskeletal pain
Statistical test: Mann-Whitney U test.

Table 8.3.3: Mean function score and statistical differences in function between people with traumatic and non-traumatic injury

	Traumatic n=18, mean±SD, median, min-max	**Non traumatic** n=27, mean±SD, median, min-max	**Statistical Tests**
Self-care subscale (range 0-20)	13.1±5.3 14, 2-20	15.5±4.9 17, 4-20	U=175.5 p=0.11, n=45
Respiration & sphincter management (range 0-40)	32.3±8.2 35.5, 11-40	35.4±6.9 38, 15-40	U=194.5 p=0.25, n=45
Mobility room & toilet (range 0-10)	7.8±3.0 10, 0-10	8.5±2.1 10, 4-10	U=219.5 p=0.54, n=45
Mobility indoor & outdoor (range 0-30)	17.1±10.2 18.5, 4-30	20.3±9.6 26, 0-30	U=201.5 p=0.33, n=45
Total SCIM (range 0-100)	70.7±21.3 74.5, 34-100	79.7±21.0 86, 28-99	U=171.5 p=0.09, n=45

Abbreviation: SD, Standard Deviation;
Statistical test: t= Independent t-test; U= Mann-Whitney U test.

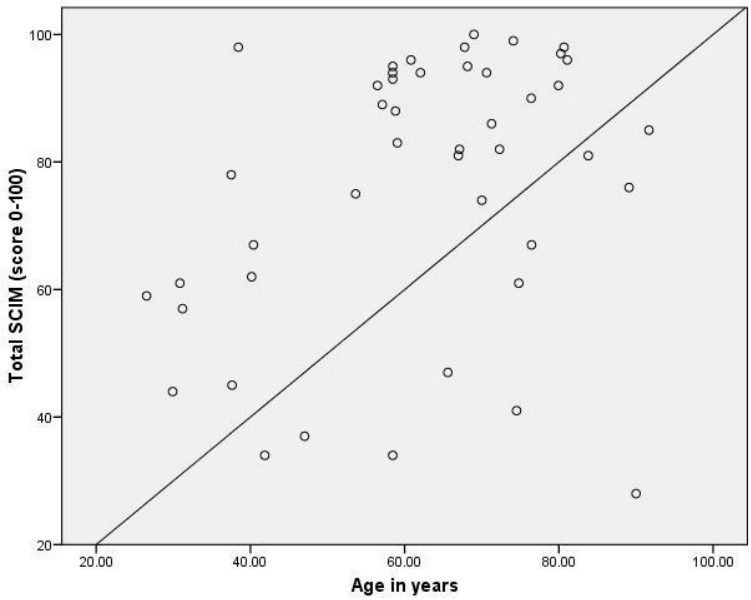

Figure 8.3.1: Scatterplot showing the correlation between total function score and age (n=45);
Abbreviations: SCIM, Spinal Cord Independence Measure.

Table 8.3.4: Mean function scores and statistical differences in function between people with tetraplegia and paraplegia

	Tetraplegia n=15, mean±SD, median, min-max	**Paraplegia** n=30, mean±SD, median, min-max	**Statistical Tests**
Self-care subscale (range 0-20)	12.3±6.1 15, 2-20	15.7±4.2 17, 6-20	U=152 p=0.07, n=45
Respiration & sphincter management (range 0-40)	32.7±8.7 38, 11-40	36.0±6.1[1] 38, 15-40	U=166.5 p=0.26, n=45
Mobility room & toilet (range 0-10)	7.6±3.0 10, 0-10	8.5±2.1 10, 4-10	U=194.5 p=0.41, n=45
Mobility indoor & outdoor (range 0-30)	15.7±11.3 9, 1-30	20.7±8.8 23.5, 0-30	U=185 p=0.33, n=45
Total SCIM (range 0-100)	68.3±25.5 61, 34-100	83.3±13.6[1] 85.5, 45-99	U=144.5 p=0.09, n=45

[1]Two outliers eliminated;
Abbreviation: SCIM: Spinal Cord Independence Measure; SD, Standard Deviation;
Statistical test: U, Mann-Whitney U test.

Table 8.3.5: Mean function scores and statistical differences in function between people divided into groups by level of injury

	Cervical n=15 mean±SD, median, min-max	**Thoracic** n=16 mean±SD, median, min-max	**Lumbar** n=14 mean±SD, median, min-max	**Statistical Tests**
Self-care subscale (range 0-20)	12.3±6.1 15, 2-20	15.2±4.1 15, 8-20	16.1±4.4 17, 6-20	H=3.55, df2 p=0.16, n=45
Respiration & sphincter management (range 0-40)	32.7±8.7 38, 11-40	36.4±5.3 39, 2-40	33.8±8.2 37.5, 15-40	F=1.00, df2 p=0.37, n=45
Mobility room & toilet (range 0-10)	7.6±3.0 10, 0-10	8.2±2.2 9, 4-10	8.9±2.0 10, 4-10	F=-0.94, df2 p=0.39, n=45
Mobility indoor & outdoor (range 0-30)	15.7±11.3 9, 1-30	20.8±9.2 25, 5-30	20.6±8.7 21.5, 0-30	F=1.28, df2 p=0.28, n=45
Total SCIM (range 0-100)	68.3±25.5 61, 34-100	80.6±16.4 84.5, 45-99	79.4±20.5 83.5, 28-98	H=1.72, df2 p=0.42, n=45

Abbreviation: SCIM: Spinal Cord Independence Measure; SD, Standard Deviation;
Statistical test: F, One-way ANOVA; H, Kruskal-Wallis H test.

8.4: GR-SCIM III; relation to pain, MSKP and LBP

Table 8.4.1: Mean function scores reported by people with and without the categories of pain

	Pain mean±SD, median, min-max		**Current LBP** mean±SD, median, min-max		**MSKP** mean±SD, median, min-max	
	Yes n=35	**No** n=10	**Yes** n=30	**No** n=13	**Yes** n=17	**No** n=25
Self-care subscale (range 0-20)	14.6±5.6 16, 2-20	14.4±3.5 15.5, 8-18	15.0±5.4 17, 2-20	13.5±4.8 15, 4-20	14.5±5.7 17, 4-20	15.6±3.8 16.5, 8-20
Respiration & sphincter management (range 0-40)	33.6±8.2 38, 11-40	36.9±2.8 37.5, 31-40	34.8±7.9[1] 37.5, 11-40	36.3±6.2[2] 38.0, 15-40	33.5±9.6 38, 11-40	35.5±5.6 37, 21-40
Mobility room & toilet (range 0-10)	8.1±2.6 10, 0-10	8.7±1.8 10, 6-10	8.4±2.2 10, 4-10	7.9±3.0 10, 0-10	8.5±2.2 10, 4-10	8.4±2.0 10, 4-10
Mobility indoor & outdoor (range 0-30)	18.5±10.3 23, 0-30	20.8±8.4 25, 6-30	19.8±9.9 23, 0-30	19.2±9.5 24, 4-30	19.1±10.8 23, 0-30	20.6±8.7 24, 6-30
Total SCIM (range 0-100)	74.8±23.2 82, 28-100	80.8±12.8 82, 62-92	77.9±21.6 84, 28-100	74.8±21.7 78, 34-97	75.6±25.2 85, 28-100	79.6±17.2 83, 44-99

[1]One outlier eliminated, [2]Four outliers eliminated.
Abbreviations: SCIM, Spinal Cord Independence Measure; LBP, Low Back Pain; MSKP, Musculoskeletal Pain.

8.5. GR-SCIM III; relation to pain/LBP days, free weeks, onset

Table 8.5.1: Mean function scores in groups divided by the number of pain or LBP days felt in the month

	Pain days felt in the month		**LBP days felt in the month**	
	1-20 days n=21 mean±SD, median, min-max	**21-Every day** n=11 mean±SD, median, min-max	**1-20 days** n=13 mean±SD, median, min-max	**21-Every day** n=18 mean±SD, median, min-max
Self-care subscale (range 0-20)	15.7±4.7 17, 6-20	13.5±6.8 13, 2-20	14.5±5.8 17, 4-20	16.3±4.2[1] 17, 8-20
Respiration & sphincter management (range 0-40)	34.7±9.0[1] 38, 1-40	33.8±6.3 37, 22-40	35.8±6.3[1] 38, 18-40	35.4±7.1 38, 15-40
Mobility room & toilet (range 0-10)	9.2±1.5[2] 10, 6-10	7.8±2.3 8, 4-10	8.0±2.2 8, 4-10	9.4±1.4[2] 10, 6-10
Mobility indoor & outdoor (range 0-30)	22.2±9.6[3] 28, 0-30	15.9±9.0 16, 1-30	18.5±11.2 23, 0-30	21.2±9.0 26, 5-30
Total SCIM (range 0-100)	90.9±19.9 94, 61-100	70.3±19.8 81, 37-98	76.1±22.8 83, 28-100	83.3±17.8[1] 92, 44-99

Table excludes people with no LBP or who did not remember number of pain days,
[1]One outlier eliminated, [2]Two outliers eliminated, [3]Three outliers eliminated.
Abbreviation: SCIM: Spinal Cord Independence Measure; SD, Standard Deviation.

Table 8.5.2: Correlations between function and the number pain or LBP days felt per month

	Self-care subscale (range 0-20)	**Respiration & sphincter management** (range 0-40)	**Mobility room & toilet** (range 0-10)	**Mobility indoor & outdoor** (range 0-30)	**Total SCIM** (range 0-100)
Pain days (n=32)	ϕ=0.50 p=0.53	ϕ=0.69 p=0.21	ϕ=0.26 p=0.54	ϕ=0.80 p=0.11	ϕ=0.91 p=0.31
LBP days (n=32)	ϕ=0.72 p=0.15	ϕ=0.69 p=0.17	ϕ=0.35 p=0.27	ϕ=0.84 p=0.03[1]	ϕ=0.88 p=0.40

[1]not significant post Bonferroni correction;
Abbreviations: SCIM, Spinal Cord Independence Measure, LBP, Low Back Pain.
Statistical test: ϕ, Phi test.

Table 8.5.3: Mean function scores in groups divided by the frequency of pain and LBP free weeks

	Pain free weeks		LBP free weeks	
	Yes, most time, frequently, sometimes n=20, mean±SD, median, min-max	**Yes, not often, rarely, no always have pain** n=12, mean±SD, median, min-max	**Yes, most time, frequently, sometimes** n=20, mean±SD, median, min-max	**Yes, not often, rarely, no always have pain** n=10, mean±SD, median, min-max
Self-care subscale (range 0-20)	15.7±4.4 17, 8-20	12.3±7.1 13.5, 2-20	15.6±5.4 17, 2-20	14.4±5.8 15, 4-20
Respiration & sphincter management (range 0-40)	34.9±7.8[1] 38, 15-40	35.5±5.0[1] 38, 26-40	35.7±7.2[1] 38, 15-40	36.2±5.5[1] 38, 22-40
Mobility room & toilet (range 0-10)	8.3±2.2 10, 4-10	7.6±3.3 10, 0-10	8.6±2.2 10, 4-10	8.6±1.9 10, 6-10
Mobility indoor & outdoor (range 0-30)	20.5±9.7 26, 0-30	16.7±11.3 16, 1-30	22.9±7.7[1] 26, 6-30	18.2±10.8 19.5, 1-30
Total SCIM (range 0-100)	77.0±24.1 88, 28-100	72.8±24.3 81, 34-98	88.7±10.1[2] 92, 61-100	76.4±22.2 81.5, 37-98

Table excludes people with no pain or who did not remember frequency of pain free weeks, [1]One outlier eliminated, [2]Two outliers eliminated.
Abbreviation: SCIM: Spinal Cord Independence Measure; LBP, Low Back Pain; SD, Standard Deviation.

Table 8.5.4: Correlations between function and the frequency of pain or LBP free weeks

	Self-care subscale	Respiration & sphincter management	Mobility room & toilet	Mobility indoor & outdoor	Total SCIM
Pain free week (n=32)	ϕ=0.70 p=0.20	ϕ=0.59 p=0.43	ϕ=0.31 p=0.53	ϕ=0.65 p=0.54	ϕ=0.80 p=0.60
LBP free weeks (n=30)	ϕ=0.65 p=0.38	ϕ=0.51 p=0.62	ϕ=0.24 p=0.62	ϕ=0.59 p=0.63	ϕ=0.82 p=0.56

Abbreviations: SCIM, Spinal Cord Independence Measure, LBP, Low Back Pain.
Statistical test: ϕ, phi test

8.6. GR-SCIM III; relation to pain extent

Table 8.6.1: Correlations between function and the number of areas with pain

	Self-care subscale	Respiration & sphincter management	Mobility room & toilet	Mobility indoor & outdoor	Total SCIM
Statistical Test	r=0.08 p=0.66	r=-0.009 p=0.96	r=0.30 p=0.09	r=0.28 p=0.12	r=0.17 p=0.36

Abbreviations: SCIM, Spinal Cord Independence Measure.
Statistical test: r, Pearson's correlation

8.7. GR-SCIM III; relation to QoL

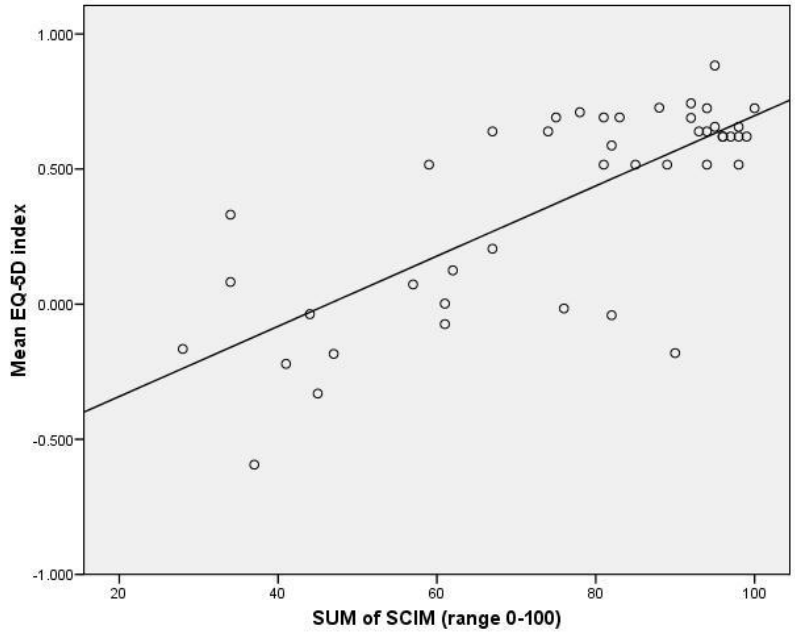

Figure 8.7.1: Scatterplot showing the correlation between function and QoL classification (EQ-5D Index) n=31.
Abbreviations: GR-SCIM, Greek Spinal Cord Independence Measure; EQ-5D, Quality of Life.

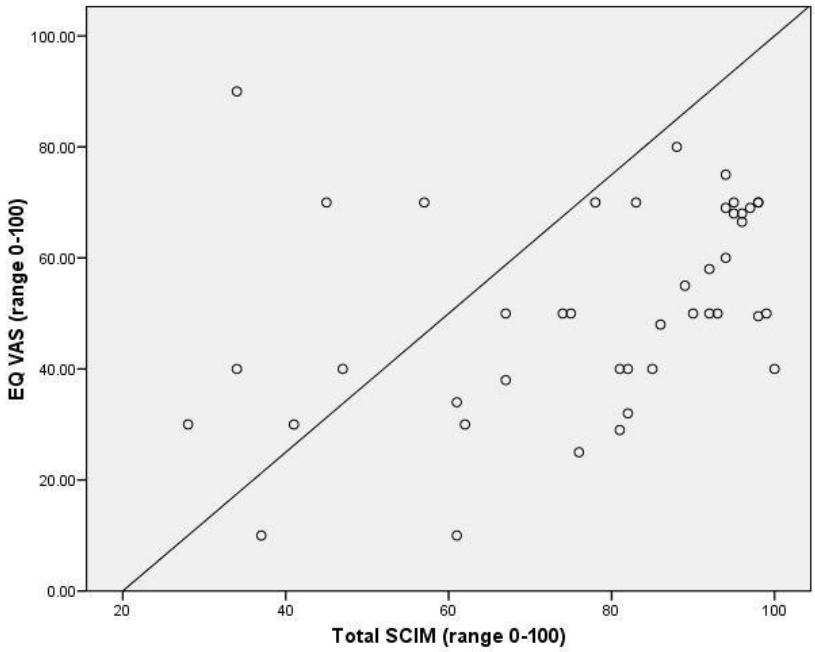

Figure 8.7.2: Scatterplot showing the correlation between function and QoL perception (EQ VAS) n=43.
Abbreviations: GR-SCIM, Greek Spinal Cord Independence Measure; EQ-VAS, Quality of Life Visual Analogue Scale.

8.8. SCIM III; relation to demographic profile characteristics

Table 8.8.1: Mean function scores and statistical differences in function between males and females

	Males n=111, mean±SD, median, min-max	**Females** n=63, mean±SD, median, min-max	**Statistical Test**
Self-care subscale (range 0-20)	11.8±5.9 18, 0-20	15.3±5.2 17, 0-20	t=-0.51, df172, p=0.60 95% CI -2.23, 1.30
Respiration & sphincter management (range 0-40)	30.0±7.1[1] 31, 11-40	28.0±7.4 29, 12-40	t=1.75, df171, p=0.08 95% CI -0.24, 4.23
Mobility room & toilet (range 0-10)	8.0±3.4 10, 0-10	8.3±2.9 10, 0-10	t=-1019, df172, p=0.23 95% CI -1.61, 0.39
Mobility indoor & outdoor (range 0-30)	13.9±8.8 11, 0-30	12.9±8.0 14, 0-30	t=0.74, df172, p=0.45 95% CI -1.65, 3.65
Total SCIM (range 0-100)	66.7±20.9[1] 70, 18-100	64.5±18.7 67, 18-100	t=0.69, df171, p=0.48 95% CI -4.07, 8.50

[1]One outlier eliminated.
Abbreviations: SCIM, Spinal Cord Independence Measure; SD, Standard Deviation; *Statistical Test*: Independent t-test

Table 8.8.2: Mean function and statistical differences of function between males or females with and without the pain or LBP

	Males mean±SD,	Statistical test of Total SCIM	Females mean±SD	Statistical test of Total SCIM
Pain				
Yes	n=12 70.5±1.1	t=0.56, df32, p=0.57, 95%CI -9.3, 16.8	n=5 56.6±21.2	U=140.5 p=0.33
No	n=12 70.5±1.1		n=76 68.3±20.2	
Current LBP				
Yes	n=46 66.0±25.7	t=0.81, df127, p=0.41, 95%CI -10.9, 4.5	n=19 62.9±21.3	t=1.2, df75, p=0.22, 95%CI -16.9, 4.1
No	n=83 69.2±18.5		n=58 69.3±9.6	
MSKP				
Yes	n=43 71.6±19.4	t=1.4, df130, p=0.15, 95%CI -13.8, 2.1	n=32 65.0±0.7	t=10.95, df75, p=0.34, 95%CI -4.9, 13.8
No	n=89 65.8±22.6		n=39 69.4±20.7	
Total SCIM (range 0-100)	66.7±20.9[1] 70, 18-100		64.5±18.7 67, 18-100	

Because of the unexpected result of people with pain, LBP or MSKP reporting slightly better, though not significant, function within gender differences were examined.
No significant differences were found within the male or female groups. Females with pain or LBP reported better function than those without pain or LBP. But, females with MSKP reported worse function than those without MSKP. Males with MSKP or LBP reported better function than those without MSKP or LBP. However, males with pain in general reported worse function than those without pain in general.
Abbreviations: SCIM, Spinal Cord Independence Measure; LBP, Low Back Pain.
Statistical tests: U, Mann-Whitney U test; t, Independent t-test.

Table 8.8.3: Mean function scores and statistical differences in function between people divided into groups by cause of injury

	Traumatic n=137, mean±SD, median, min-max	**Non traumatic** n=37, mean±SD, median, min-max	**Statistical Tests**
Self-care subscale (range 0-20)	14.6±5.9 17, 0-20	16.5±4.2 18, 2-20	U=2103.5, p=0.10
Respiration & sphincter management (range 0-40)	29.3±7.4[1] 30, 11-40	29.6±6.0[1] 29.5, 17-40	t=-0.25, df170, p=0.79 95% CI -2.99, 2.30
Mobility room & toilet (range 0-10)	7.8±3.4 10, 0-10	8.3±2.5 10, 0-10	U=2497.5, p=0.88
Mobility indoor & outdoor (range 0-30)	13.5±8.6 12, 0-30	13.4±8.1 10, 3-30	t=0.05, df172, p=0.95 95% CI -3.03, 3.21
Total SCIM (range 0-100)	65.5±21.2[1] 69.5, 18-100	68.4±14.7[1] 66.5, 40-100	U=2411.5, p=0.89

[1]One outlier eliminated.
Abbreviations: SCIM, Spinal Cord Independence Measure.
Statistical test: t, Independent t-test; U, Mann-Whitney U test.

Table 8.8.4: Mean function scores and statistical differences in function between people divided into groups by level of injury

	Tetraplegia n=103, mean±SD, median, min-max	**Paraplegia** n=116, mean±SD, median, min-max	**Statistical Tests**
Self-care subscale (range 0-20)	12.7±6.6 15, 0-20	16.9±3.4[1] 18, 8-20	t=-5.92, df216 **p≤0.001***** 95% CI -5.5 - -2.7
Respiration & sphincter management (range 0-40)	29.7±8.3[1] 30, 11-40	30.8±6.5 32, 12-40	t=-1.12, df216 p=0.26 95% CI -3.17, 0.87
Mobility room & toilet (range 0-10)	7.0±3.8 9, 0-10	9.1±1.5 10, 4-10	t=-5.35, df212 p<0.001 95% CI -2.9, 1.9 U=4223, **p≤0.001****
Mobility indoor & outdoor (range 0-30)	13.3±9.5 9, 0-30	15.8±8.1[3] 15.5, 0-30	t=-2.04, df217 p=0.04 95% CI -4.9, 0.09
Total SCIM (range 0-100)	62.5±25.5 65, 3-100	73.4±13.6[2] 73, 40-99	t=-3.97, df214 **p≤0.001*** 95% CI -16.35, -5.5

[1]Two outlier eliminated, [2]Three outliers eliminated, [3]Five outliers eliminates, ***Significant at p≤0.001 level; **In bold:** remained significant following application of the Bonferroni correction.
Abbreviations: SCIM, Spinal Cord Independence Measure; SD, Standard Deviation.
Statistical tests: t, Independent t-test; U, Mann-Whitney U test.

Table 8.8.5: Mean function scores and statistical differences in function between people divided into groups by level of injury

	Cervical n=88, mean±SD, median, min-max	**Thoracic** n=57, mean±SD, median, min-max	**Lumbar** n=29, mean±SD, median, min-max	**Statistical Test**
Self-care subscale (range 0-20)	12.8±6.7 15, 0-20	17.±3.4 18, 8-20	17.6±2.8 18, 9-20	H=12.58, df2 **p≤0.001*** **
Respiration & sphincter management (range 0-40)	29.2±8.1[1] 29, 11-40	29.4±5.6[2] 30, 15-40	30.2±5.9 31, 18-40	H=0.001, df2 p=0.97
Mobility room & toilet (range 0-10)	6.9±3.9 9, 0-10	8.8±1.8 10, 3-10	9.3±1.3 10, 6-10	H=5.99, df2 p=0.014[3]
Mobility indoor & outdoor (range 0-30)	12.9±9.7 9.5, 0-30	12.9±7.1 10, 4-30	16.5±6.6 17, 6-30	H=1.13, df2 p=0.28
Total SCIM (range 0-100)	61.5±25.6 65.5, 3-100	68.8±11.9[2] 69, 40-96	73.7±10.6 73, 53-96	H=1.36, df2 p=0.24

[1]One outlier eliminated, [2]Two outliers eliminated, [3]not significant post Bonferroni correction
***Significant at p≤0.001 level; **In bold:** remained significant following application of the Bonferroni correction;
Abbreviations: SCIM, Spinal Cord Independence Measure; SD, Standard Deviation;
Statistical Test: Kruskall-Wallis H Test.

Table 8.8.6: Two group comparisons for total function scores between groups divided by level of injury

		Thoracic	**Lumbar**
Self-Care	**Cervical**	U=1640.5 **p≤0.001*** **	U=755 **p≤0.001*** **

***Significant at p≤0.001 level,
in bold: remained significant following Bonferroni post hoc;
Abbreviations: SCIM, Spinal Cord Independence Measure.
Statistical test: U, Mann-Whitney U test.

8.9. SCIM III; relation to pain, LBP and MSKP

Table 8.9.1: Mean function scores reported by people with and without the categories of pain

	Pain mean±SD, median, min-max		**Current LBP mean±SD, median, min-max**		**MSKP mean±SD, median, min-max**	
	Yes n=156	**No** n=9	**Yes** n=113	**No** n=55	**Yes** n=66	**No** n=106
Self-care subscale (range 0-20)	16.0±4.4[6] 18, 3-20	11.3±8.1 13, 2-20	15.8±4.4[3] 18, 6-20	14.2±7.1 18 0-20	15.6±4.5[1] 18, 2-20	15.2±30.6[3] 18, 2-20
Respiration & sphincter management (range 0-40)	29.5±7.8[1] 30, 11-40	24.6±10.1 24, 13-40	29.5±7.1 30, 11-40	28.6±7.7[1] 29, 13-40	29.4±7.4 30, 12-40	29.2±7.2[1] 30, 11-40
Mobility room & toilet (range 0-10)	8.0±3.0 10, 0-10	5.3±5.1 8, 0-10	8.6±2.4 10, 0-10	7.2±4.1[4] 10, 0-10	9.0±2.1[5] 10, 0-10	7.6±3.5 10, 0-10
Mobility indoor & outdoor (range 0-30)	13.6±8.4 11, 0-30	11.2±10.7 7, 2-30	14.1±8.1 13.0, 0-30	12.3±9.3 8, 2-30	14.3±8.5 12, 0-30	12.9±8.5 10, 0-30
Total SCIM (range 0-100)	66.5±19[2] 69, 18-100	52.4±30.9 53, 18-100	68.0±17.2[2] 68.5, 31-100	62.3±24.7[2] 68, 18-100	68.0±17.9[1] 70, 29-100	64.7±21.1[1] 68, 18-100

[1]One outlier eliminated, [2]Two outliers eliminated, [3]Four outliers eliminated, [4]Six outliers Eliminated, [5]Seven outliers eliminated, [6]Nine outliers eliminated.
Abbreviations: SCIM, Spinal Cord Independence Measure; LBP, Low Back Pain; MSKP, Musculoskeletal Pain.

8.10. SCIM III; relation to pain/LBP days, free weeks, onset

Table 8.10.1: Mean function scores in groups divided by the number of pain days felt per month

	1-9 days n=28 mean±SD, median, min-max	**10-20 day** n=28 mean±SD, median, min-max	**21-30 days** n=19 mean±SD, median, min-max	**Every day** n=120 mean±SD, median, min-max
Self-care subscale (range 0-20)	17.6±4.1 18.5, 3-20	13.8±7.2 18, 0-20	15.4±6.1 18, 6-20	15.0±5.2 17, 0-20
Respiration & sphincter management (range 0-40)	33.4±4.7 34.5, 23-40	29.4±9.5 32, 0-40	29.2±8.4 33, 12-40	28.8±7.0 29, 11-40
Mobility room & toilet (range 0-10)	9.1±2.5 10, 0-10	7.2±4.0 10, 0-10	8.1±3.5 10, 0-10	8.0±2.9 10, 0-10
Mobility indoor & outdoor (range 0-30)	14.4±8.4 11.5, 4-30	11.6±8.1 9, 3-30	10.0±8.0 7, 0-30	14.2±8.3 15, 0-30
Total SCIM (range 0-100)	74.5±15.7 76, 30-96	62.0±25.9 71, 3-100	62.7±22.2 68, 21-100	66.0±18.8 67, 23-100

Table excluded people with no LBP or who did not remember.
Abbreviations: SCIM, Spinal Cord Independence Measure; SD, Standard Deviation.

Table 8.10.2: Mean function scores in groups divided by the number of LBP days felt per month

	1-9 days n=40 mean±SD, median, min-max	**10-20 day** n=28 mean±SD, median, min-max	**21-30 days** n=18 mean±SD, median, min-max	**Every day** n=65 mean±SD, median, min-max
Self-care subscale (range 0-20)	15.5±5.8 18, 1-20	16.9±4.6 18, 0-20	17.1±3.3 18, 10-20	14.8±4.7 16, 2-20
Respiration & sphincter management (range 0-40)	29.5±7.1 30, 11-40	30.9±8.6 32.5, 0-40	28.±8.3 28, 12-40	29.0±7.3 29.5, 12-40
Mobility room & toilet (range 0-10)	8.5±2.9 10, 0-10	9.0±2.6 10, 0-10	9.0±21.3 9, 6-10	7.9±2.8 10, 0-10
Mobility indoor & outdoor (range 0-30)	12.3±7.0 10, 0-28	17.4±7.6 17, 3-30	13.0±7.4 13, 4-29	14.3±8.4 14, 0-30
Total SCIM (range 0-100)	65.8±19.1 70, 21-91	74.2±20.0 77.5, 3-100	67.5±15.1 73, 32-86	66.1±18.4 66.5, 31-100

Table excluded people with no LBP or who did not remember.
Abbreviations: SCIM, Spinal Cord Independence Measure; SD, Standard Deviation.

Table 8.10.3: Correlations between function and the number of pain or LBP days felt per month

	Self-care subscale	Respiration & sphincter management	Mobility room & toilet	Mobility indoor & outdoor	Total SCIM
Pain days	ρ=-0.11 p=0.15 n=195	ρ=-0.19 p≤0.01[1] n=195	ρ=-0.08 p=0.30 n=195	ρ=-0.09 p=0.23 n=195	ρ=-0.07 p=0.36 n=195
LBP days	ρ=-0.18 p=0.04[1] n=151	ρ=-0.07 p=0.40 n=151	ρ=-0.15 p=0.08 n=151	ρ=-0.02 p=0.77 n=151	ρ=-0.80 p=0.37 n=151

[1]not significant post Bonferroni correction;
Abbreviations: SCIM, Spinal Cord Independence Measure; LBP, Low Back Pain.
Statistical test: ρ, Spearman's rank correlation rho.

Table 8.10.4: Mean function scores in groups divided by the frequency of pain free weeks

	Yes, most time n=12 mean±SD, median, min-max	**Yes, frequently** n=15 mean±SD, median, min-max	**Yes, sometimes** n=17 mean±SD, median, min-max	**Yes, but not often** n=12 mean±SD, median, min-max	**Yes, but rarely** n=18 mean±SD, median, min-max	**No, I always have pain** n=70 mean±SD, median, min-max
Self-care subscale Range 0-20	16.1±6.8 19, 1-20	17.6±2.1 18, 15-20	11.6±6.9 12, 0-20	19.2±1.0 19.5, 18-20	18.8±6.0 18, 3-20	14.8±5.3 16, 0-20
Respiration & sphincter management Range 0-40	31.5±7.1 33, 18-40	35.0±3.7 35, 28-40	28.3±6.6 30, 15-38	31.3±6.3 33, 23-40	27.5±7.4 28, 15-40	28.5±7.7 29, 0-40
Mobility room & toilet Range 0-10	8.1±3.6 10, 0-10	9.7±0.6 10, 8-10	6.5±4.3 18, 0-10	Constant	8.0±2.9 9.5, 0-10	7.9±3.1 10, 0-10
Mobility indoor & outdoor Range 0-30	12.4±8.6 10, 3-28	16.1±8.9 18, 7-30	9.8±8.7 7, 0-30	13.7±3.5 14, 9-19	13.5±8.2 11.5, 3-29	13.8±8.5 13, 0-30
Total SCIM Range 0-100	68.2±22.6 78, 25-91	78.4±12.4 79, 63-100	56.3±23.8 60, 18-96	74.2±7.6 73, 62-85	63.9±20.6 73, 23-86	65.0±20.1 66.5, 3-100

Table excludes people with no pain or who did not remember any pain breaks.
Abbreviations: SCIM, Spinal Cord Independence Measure; SD, Standard Deviation.

Table 8.10.5: Mean function scores in groups divided by the frequency of LBP free weeks

LBP free weeks	**Yes, most time** n=17 mean±SD, median, min-max	**Yes, frequently** n=9 mean±SD, median, min-max	**Yes, sometimes** n=13 mean±SD, median, min-max	**Yes, but not often** n=11 mean±SD, median, min-max	**Yes, but rarely** n=24 mean±SD, median, min-max	**No, I always have pain** n=45 mean±SD, median, min-max
Self-care subscale Range 0-20	18.4±2.7 20, 11-20	18.0±2.8 18, 16-20	14.7±4.6 15, 8-20	18.0±1.2 18, 17-20	15.4±5.6 18, 3-20	14.6±5.0 4.99, 0-20
Respiration & sphincter management Range 0-40	32.4±3.2 33, 28-38	34.5±0.7 34.5, 34-35	26.1±10.4 26, 11-40	28.0±3.5 29, 23-32	29.4±7.7 31.50, 16-40	28.1±8.1 29, 0-40
Mobility room & toilet Range 0-10	9.5±0.8 10, 8-10	9.6±1.1 10, 7-10	9.4±1.3 10, 7-10	9.5±1.0 10, 7-10	8.1±3.4 10, 0-10	8.0±2.8 9.5, 0-10
Mobility indoor & outdoor Range 0-30	12.6±6.6 10, 7-28	16.1±8.9 18, 7-30	18.0±9.5 15, 3-30	15.8±8.7 13, 8-29	15.1±7.7 15.5, 3-30	14.3±8.6 13.5, 0-30
Total SCIM Range 0-100	72.9±9.2 73, 54-91	73.5±7.8 73.5, 68-79	68.4±22.9 73, 33-91	71.2±9.0 73, 62-82	68.0±19.9 74, 27-96	65.1±19.9 65.5, 3-100

Table excludes people with no LBP or who did not remember any LBP breaks.
Abbreviations: SCIM, Spinal Cord Independence Measure; SD, Standard Deviation.

8.11. SCIM III; relation to pain extent

Table 8.11.1: Correlations between function score and the number of areas with pain

	Self-care subscale	**Respiration & sphincter management**	**Mobility room & toilet**	**Mobility indoor & outdoor**	**Total SCIM**
Statistical test	r=-0.14 p=0.057 n=142	r=-0.12 p=0.10 n=142	r=0.01 p=0.83 n=142	r=-0.03 p=0.66 n=142	r=-0.08 p=0.21 n=142

Abbreviations: SCIM, Spinal Cord Independence Measure.
Statistical test: r, Pearson's correlation.

Appendix 9; Cross-national analysis

Supplement for Chapter 9

Part 1; 9.a. Demographic profile characteristics and pain presence across nations

9.a.1. Bonferroni Correction

Table 9.a.1.1: Main variables used in analysis of socio-demographic profile of respondents in cross-national analysis and alpha value set following Bonferroni correction

Main Variable	Tests with following variables		Alpha value following Bonferroni correction
Pain (in general)	1) Country 2) Gender 3) Cause of injury 4) Age	5) Type of injury 6) Time since injury	0.05/6=0.008 p≤0.008
Back pain	1) Country 2) Gender 3) Cause of injury 4) Age	5) Type of injury 6) Time since injury	0.05/6=0.008 p≤0.008
Current LBP	1) Country 2) MSKP 3) Gender 4) Cause of injury	5) Age 6) Type of injury 7) Time since injury	0.05/7=0.007 p≤0.007
Lifetime LBP (post iSCI)	1) Country 2) MSKP 3) Gender 4) Cause of injury	5) Age 6) Type of injury 7) Time since injury	0.05/7=0.007 p≤0.007
LBP over last 1 month	1) Country 2) MSKP 3) Gender 4) Cause of injury	5) Age 6) Type of injury 7) Time since injury	0.05/7=0.007 p≤0.007
LBP over last 3 months	1) Country 2) MSKP 3) Gender 4) Cause of injury	5) Age 6) Type of injury 7) Time since injury	0.05/7=0.007 p≤0.007
MSKP	1) Country 2) Gender 3) Cause of injury	4) Age 5) Type of injury 6) Time since injury	0.05/6=0.008 p≤0.008

Abbreviations: LBP, Low Back Pain; iSCI, incomplete Spinal Cord Injury; MSKP, Musculoskeletal Pain;
USA, United Stated of America; UK, United Kingdom

9.a.2. Demographic profile characteristics

Table 9.a.2.1: General demographic profile characteristics of respondents across nations. Differences between groups

	Mean ± SD, % or min-max,			Statistical tests	Two group and post hoc analysis
	USA	UK	GR		
Sex (M/F)	66.4/33.6, n=122	57.7/42.3, n=52	56.1/43.9, n=41	χ^2=2.01, df2, p=0.36	
Age (years, mean ± SD, min-max)	45.5±10.8 19.8-66.8 n=122	50.9±13.0 26.1-73.2 n=50	61.9±17.4 26.5-91.7 n=45	H=34.0, df2 **p≤0.001*****	UK vs GR U=608, **p≤0.001***** UK vs USA U=2153, p=0.009[2] USA vs GR U=1106.5, **p≤0.001*****
Time since injury (years, mean ± SD, min-max)	10.8±10.9 0.3-44.2 n=121	13.8±11.9 0.9-43.8 n=52	11.9±8.1 1.4-34.3 n=45	H=3.853, df2 p=0.14	
Age at injury (years, mean ± SD, min-max)	34.4±13.7 0.0-64.3 n=115	37.0±16.7 0.0-68.3 n=52	50.9±15.9 20.8-78.3 n=45	F=20.15, df2 **p≤0.001*****	UK vs GR I-J=-13.9, **p≤0.001***** UK vs USA I-J=-2.58, p=0.56 USA vs GR I-J=-16.5, **p≤0.001*****
Mother Tongue (%) English or Greek Other	 95.9 4.1	 92.3 7.7	 97.8[1] 2.2	(UK vs USA only) χ^2=0.33 p=0.45	
Marital status (%) Married Living with partner In a relationship Separated/Divorced Widowed Single Other	n=120 56.7 5 1.7 10.8 2.5 22.5 0.8	n=51 60.8 7.8 3.9 11.8 3.9 11.8 0.0	n=43 53.5 9.3 4.7 0.0 20.9 11.6 0.0	χ^2=28.7, df2, p=0.004** χ^2=28.3, df2, **p≤0.001***** χ^2=0.57, df2, p=0.75 χ^2=0.0, df2, p=1 χ^2=2.57, df2, p=0.1 χ^2=6.14, df2, p=0.04[2] χ^2=24.3, df2, **p≤0.001***** n/a	<u>Married</u> UK vs GR χ^2=1.18, p=0.27 UK vs USA χ^2=13.82, **p≤0.001***** USA vs GR χ^2=22.2, **p≤0.001***** <u>Widowed</u> UK vs GR χ^2=4.45, p=0.03[2] UK vs USA χ^2=0.2, p=0.65 USA vs GR χ^2=3.0, p=0.08 <u>Single</u> UK vs GR χ^2=0.09, p=0.76 UK vs USA χ^2=13.36, **p≤0.001***** USA vs GR χ^2=15.12, **p≤0.001*****

[1] For the Greek language, [2]not significant post Bonferroni correction; ***Significant at p≤0.001 level, in bold: significant following application of the Bonferroni correction or post hoc analysis; *Statistical tests*: χ^2, Chi square; H, Kruskal-Wallis H test; U, Mann-Whitney U test

Table 9.a.2.2: General demographic profile characteristics of respondents across nations. Differences between groups

	Mean ± SD, % or min-max			**Statistical tests**	**Two group and post hoc analysis**
	USA	UK	GR		
Education (%)	n=121	n=50	n=44	χ^2=58.8,df12,**p≤0.001***	
PhD or equivalent	4.9	2	0.0	χ^2=3.57,df2,p=0.059	
Master's	15.6	16	6.8	χ^2=13.4,df2,**p≤0.001***	
Bachelors Degree	18	22	31.8	χ^2=4.12,df2,p=0.12	
College or equivalent	26.2	28	2.3	χ^2=30.9,df2,**p≤0.001***	
High School	29.5	10	25	χ^2=31.1,df2,**p≤0.001***	
Other	4.9	6	34.1	χ^2=12.2,df2,p=0.02[1]	
No diploma/degree	.8	16	0.0	χ^2=1.0,df2,p=0.31	
In two categories				χ^2=7.41,df12,p=0.02[1]	Above vs Below highschool
Below High School	29.5	10	25		UK vs GR χ^2=3.72, p=0.053
Above High School	70.5	90	75		UK vs USA χ^2=7.43, **p=0.006****
					USA vs GR χ^2=0.32, p=0.56
Cause of injury (%)	n=122	n=52	n=45	χ^2=26.08,df2,**p<0.001****	UK vs GR χ^2=16.9, **p≤0.001***
Traumatic	77.9	80.8	40		UK vs USA χ^2=0.18, p=0.66
Non-traumatic	22.1	19.2	60		USA vs GR χ^2=21.5, **p≤0.001***
Type of injury (%)	n=122	n=52	n=45	χ^2=4.84,df2,p=0.08	
Incomplete tetraplegia	52.5	46.2	33.3		
Incomplete paraplegia	47.5	53.8	66.7		
Level of injury (%)	n=122	n=52	n=45	χ^2=7.10,df4,p=0.13	
Cervical	52.5	46.2	33.3		
Thoracic	32	36.5	35.6		
Lumbar	15.6	17.3	31.1		

[1]not significant post Bonferroni correction; **Significant at p≤0.01 level, ***Significant at p≤0.001 level, in bold: significant following application of the Bonferroni correction or post hoc analysis;

Abbreviation: PhD, Doctor of Philosophy. *Statistical test*: χ^2, extended or Pearson's chi square

Table 9.a.2.3: General demographic profile characteristics of respondents across nations. Differences between groups

	Mean ± SD, % or min-max			Statistical tests	Two group and post hoc analysis
	USA	UK	GR		
Employment (%)[2]	n=122	n=52	n=45		Voluntary work
Employed	18.85	19.2	15.55	χ^2=4.64,df2,p=0.09	UK vs GR χ^2=7.97, p=0.005**
Self-employed	33.6	7.7	22.2	χ^2=3.46,df2,p=0.17	UK vs USA χ^2=4.07, p=0.04*
Voluntary work	9.8	21.2	2.2	χ^2=9.21,df2,p≤0.01[1]	USA vs GR χ^2=2.65, p=0.1
Working from home	11.5	13.5	0.0	χ^2=6.17,df2,p=0.04[1]	Working from home
Receive health benefits	21.3	26.9	4.4	χ^2=8.64,df2,p=0.013[1]	UK vs GR χ^2=6.52, p≤0.01**
Looking for a job	6.6	5.8	0.0	χ^2=3.04,df2,p=0.21	UK vs USA χ^2=0.13, p=0.71
Unemployed but was working before iSCI	23.8	11.5	0.0	χ^2=14.8,df2,**p≤0.001*****	USA vs GR χ^2=5.63, p≤0.01**
					Receive health benefits
Unable to work due to iSCI	30.3	26.9	8.9	χ^2=8.15,df2,p≤0.01[1]	UK vs GR χ^2=8.8, p=0.003*
Unemployed and never had a paid job	0.8	1.9	0.0	χ^2=1.01,df2,p=0.6	UK vs USA χ^2=0.64, p=0.42
					USA vs GR χ^2=6.7, p≤0.01**
Homemaker	9.0	3.8	2.0	χ^2=2.04,df2,p=0.36	Unemployed but was working
Retired	8.2	38.5	23	χ^2=40.5,df2,**p≤0.001*****	UK vs GR χ^2=5.5, p≤0.01**
Student	7.4	1.9	0.0	χ^2=5.19,df2,p=0.07	UK vs USA χ^2=3.39, p=0.06
Other	5.7	5.8	2.2	χ^2=0.93,df2,p=0.62	USA vs GR χ^2=12.94, p≤0.001***
					Unable to work due to iSCI
					UK vs GR χ^2=5.19, p=0.02*
					UK vs USA χ^2=0.20, p=0.65
					USA vs GR χ^2=8.15, p=0.004**
					Retired
					UK vs GR χ^2=1.56, p=0.21
					UK vs USA χ^2=23.4, p≤0.001***
					USA vs GR χ^2=38.1, p≤0.001***
Working hours (mean ± SD, mix-max)	33.57 ± 16.45, 3-60, n=27	19.79 ± 13.26, 2-40, n=17	40, n=1	H=10.25, df2, p=0.006**	UK vs GR U=0.5, p=0.12 UK vs USA U=104.5, p=0.002** USA vs GR U=11.5, p=0.79

[1]not significant post Bonferroni correction; [2]Total sums to greater than 100% because respondents were allowed to choose more than one option; *Significant at p≤0.05 level, **Significant at p≤0.01 level, ***Significant at p≤0.001 level, **in bold:** significant following application of the Bonferroni correction or post hoc analysis, [1]not significant post Bonferroni correction; Abbreviations: iSCI, incomplete Spinal Cord Injury. *Statistical tests*: χ^2, extended or Pearson's Chi square.

Table 9.a.2.4: Cause of traumatic injury for respondents across nations. Differences between groups

	USA	UK	GR	Statistical test used for group differences	Two group and post hoc analysis
Cause of Traumatic Injury (%)	n=94	n=52	n=45		
Road Traffic Accident	56.3	35.8	61.2	χ^2=37.8, df2, **p≤0.001*****	Road Traffic Accident
Bicycle Accident	2.1	14.3	5.6		UK vs GR χ^2=0.61, p=0.43
Car Accident	38.3	16.7	22.2		UK vs USA χ^2=19.63,p≤0.001***
Motorbike Accident	13.8	4.8	16.7		USA vs GR χ^2=25.8, p≤0.001***
Pedestrian accident	0.0	0.0	16.7		
Gunshot	2.1	0.0	0.0		
Violence Accident	1.1	0.0	0.0	Constant	
Work Related Accident	3.2	2.4	0.0	χ^2=1.0, df1, p=0.31	
Falling off Ladder/Stairs	2.1	0.0	0.0		
Falling off scaffolding	0.0	2.4	0.0		
Other work related	1.1	0.0	0.0		
Domestic Related Accident	5.3	7.2	16.8	χ^2=0.72, df2, p=0.69	
Falling off Stairs	3.2	4.8	0.0		
Falling out of window	0.0	0.0	5.6		
Tripping over object on floor	2.1	0.0	5.6		
Slippery floor	0.0	2.4	5.6		
Other type of fall	10.6	11.9	11.1	χ^2=5.76, df2, p=0.056	
Sports Accident	23.6	42.9	11.1	χ^2=11.4, df2, **p=0.003****	Sports Accident
Diving/scuba diving/body surfing/swimming	6.5	7.1	11.1		UK vs GR χ^2=9.0, p=0.003** UK vs USA χ^2=0.29, p=0.59
Paragliding	0.0	7.1	0.0		USA vs GR χ^2=11.8, p≤0.001***
Motorbike/racing	4.3	0.0	0.0		
Skiing/snowboarding	0.0	4.8	0.0		
Climbing	0.0	4.8	11.1		
Horse riding	0.0	4.8	0.0		
Other type sport	7.5	4.8	0.0		
Other Traumatic Cause of Injury	29.7	9.5	0.0	χ^2=0.11, df1, p=0.73	

Significant at p≤0.01 level, ***Significant at p≤0.001 level; **in bold: significant following application of the Bonferroni correction or post hoc analysis.
Statistical tests: χ^2, extended or Pearson's chi square.

Table 9.a.2.5: Cause of traumatic injury for respondents across nations. Differences between groups

	USA	UK	GR	Statistical test used for group differences	Two group and post hoc analysis
Cause of Non-Traumatic Injury (%)	n=27	n=10	n=45		
Vascular	33.3	20	5.7	χ^2=9.5, df2, p=0.009[1]	
Embolism	11.1	10	0.0		
Epidural Haemorrhage	7.4	0.0	2.9		
Hypotension leading to loss of blood supply	0.0	0.0	2.9		
Vascular other	14.8	10	0.0		
Cancerous	3.7	0.0	5.7	χ^2=0.33, df1, p=0.56	
Inflammations & Infections	3.7	10	2.9	χ^2=0.5, df2, p=0.77	
Transverse Myelitis	3.7	10	0.0		
Sarcoidosis	0.0	0.0	2.9		
Degenerative	3.7	3.7	42.9	χ^2=12.4, df2, **p=0.002****	
Osteoarthritis	0.0	0.0	5.7		<u>Degenerative</u>
Osteoporosis	0.0	0.0	20		UK vs GR χ^2=9.0, p=0.003**
Rheumatoid Arthritis	0.0	0.0	17.1		UK vs USA χ^2=0.66, p=0.41
Spinal Deformity	14.8	30	0.0	χ^2=0.0, df1, p=1.0	USA vs GR χ^2=5.55, p≤0.01**
Spinal Bifida	3.7	0.0	0.0		
Spondylolisis/spinal hernia/stenosis	11.1	20	0.0		
Kyphoscoliosis	0.0	10	0.0		
Other	0.0	0.0	2.9		
Neurological Disorders	3.7	0.0	11.8	χ^2=0.33, df1, p=0.56	
Multiple Sclerosis	3.7	0.0	8.6		
Cerebral Palsy	0.0	0.0	2.9		
Mistake at surgery	7.4	10	0.0	χ^2=0.33, df1, p=0.56	
Other not above	14.8	10	5.7	χ^2=1.8, df1, p=0.18	
More than one of the above reasons	14.8	10	22.9	χ^2=4.5, df2, p=0.10	

[1]not significant post Bonferroni correction; *Significant at p≤0.05 level, **Significant at p≤0.01 level; **in bold:** significant following application of the Bonferroni correction or post hoc analysis; [1]not significant post Bonferroni correction; *Statistical tests*: χ^2, extended or Pearson's chi square.

Table 9.a.2.6: General demographic profile characteristics of participants across nations

	USA (%)	UK (%)	GR (%)		USA (%)	UK (%)	GR (%)
Neuropathic pain	n=113	n=50	n=32	**Upper limb pain**	n=113	n=50	n=32
Above level of injury				Yes	19.5	24	18.8
Yes	8.8	16	3.1	No	80.5	76	81.3
No	91.3	84	96.9				
At-level of injury							
Yes	31.9	40	25				
No	68.1	60	75				
Below-level of injury							
Yes	68.1	72	25				
No	31.9	28	75				
First treated after iSCI in a:				Ethnic group (%) (n=111)	n=111	n=50	n=45
National/ State/ Public hospital	24	84.6	88.9	White – UK	5	86	0.0
Private hospital	54.5	7.7	4.4	White – European non UK, non Greek	11	10	0.0
National/State/Public rehabilitation centre	1.7	0	2.2	White – Americans (including American Indians, and Spanish/ Hispanic)	21.9	0.0	100
Private rehabilitation centre	4.1	1.9	2.2			0.0	0.0
National/State/Public iSCI centre	1.7	5.8	0			0.0	0.0
Private iSCI centre	4.1	0	0	White Greek	0.0	0.0	0.0
Medical centre/trauma centre	5	0	0	White – Other white	38.7	0.0	0.0
Army hospital	2.5	0	2.2	Other West European	3.4	0.0	0.0
Other	2.5	0	0	Other Asian	1.7	2.0	0.0
				Black (including Caribbean & other Black)	1.6	0.0	0.0
				Mixed – White & Asian	1.7	2.0	0.0
				Mixed – Other mixed	5	0.0	0.0
Insurance used for iSCI treatment							
National/ State/ Public	9.8	88.5	84.4				
Private	53.3	5.8	6.7				
Both national/state/public and private	9.8	3.8	8.2				
None	4.1	1.9	0				
Medicare	13.1	0	0				
Other	11.5	0	0				

Abbreviation: iSCI, incomplete Spinal Cord Injury

9.a.3: Pain, MSKP and LBP; relation to demographic profile characteristics

Table 9.a.3.1: Presence of pain catagories, within each national group, divided by gender

		Total group			Only people with pain		
		USA %	UK %	GR %	USA %	UK %	GR %
Pain in general	Male	93, n=81	96.7, n=30	73.9, n=23	n/a	n/a	n/a
	Female	95.1, n=41	95.5, n=22	88.9, n=18			
MSKP	Male	32.1, n=81	36.7, n=30	28.6, n=21	34.2, n=76	37.9, n=29	40, n=15
	Female	46.2, n=39	50, n=22	52.9, n=17	48.6, n=37	52.4, n=21	60, n=15
Back pain	Male	76.5, n=81	73.3, n=30	71.4, n=21	76.5, n=81	73.3, n=30	71.4, n=21
	Female	79.5, n=39	81.8, n=22	88.2, n=17	79.5, n=39	81.8, n=22	88.2, n=17
LBP lifetime	Male	70.4, n=81	70, n=30	65.2, n=23	70.4, n=81	70, n=30	65.2, n=23
	Female	78, n=41	81.8, n=22	88.9, n=18	78, n=41	81.8, n=22	88.9, n=18
LBP current	Male	76.5, n=81	73.3, n=30	71.4, n=21	64.6, n=79	65.5, n=29	63.6, n=22
	Female	79.5, n=39	81.8, n=22	88.2, n=17	68.4, n=38	77.3, n=22	82.4, n=17
LBP over 1 month	Male	63.8, n=81	65.5, n=29	63.6, n=22	63.8, n=81	65.5, n=29	63.6, n=22
	Female	68.4, n=38	81.8, n=22	88.2, n=17	68.4, n=38	81.8, n=22	88.2, n=17
LBP over 3 months	Male	66.3, n=80	65.5, n=29	63.9, n=22	66.3, n=80	65.5, n=29	63.9, n=22
	Female	73, n=37	81.8, n=22	88.2, n=17	73, n=37	81.8, n=22	88.2, n=17

Abbreviations: MSKP, Musculoskeletal Pain; LBP, Low Back Pain

Table 9.a.3.2: Presence of pain categories, within each national group, divided by cause of injury

		Total group			Only people with pain		
		USA %	**UK** %	**GR** %	**USA** %	**UK** %	**GR** %
Pain in general	Traumatic	92.6, n=95	95.2, n=42	72.2, n=18	n/a	n/a	n/a
	Non-Traumatic	100, n=27	100, n=10	81.5, n=27			
MSKP	Traumatic	31.2, n=93	42.9, n=42	26.7, n=15	33.7, n=86	45, n=40	40, n=10
	Non-Traumatic	55.6, n=27	40, n=10	48.1, n=27	55.6, n=27	40, n=10	59.1, n=22
Back pain	Traumatic	73.1, n=93	78.6, n=42	66.7, n=15	79.1, n=86	82.5, n=40	100, n=10
	Non-Traumatic	92.6, n=27	70, n=10	81.5, n=27	92.6, n=27	70, n=10	100, n=22
LBP lifetime	Traumatic	68.4, n=95	76.2, n=42	61.1, n=18	73.9, n=88	80, n=40	84.6, n=13
	Non-Traumatic	88.9, n=27	70, n=10	81.5, n=27	88.9, n=27	70, n=10	100, n=22
LBP current	Traumatic	61.1, n=90	70.7, n=41	56.3, n=16	66.3, n=83	74.4, n=39	81.8, n=11
	Non-Traumatic	81.5, n=27	70, n=10	77.8, n=27	81.5, n=27	70, n=10	95.5, n=22
LBP over 1 month	Traumatic	61.5, n=91	73.2, n=41	56.3, n=16	66.7, n=84	76.9, n=39	81.8, n=11
	Non-Traumatic	77.8, n=27	70, n=10	81.5, n=27	77.8, n=27	70, n=10	100, n=22
LBP over 3 months	Traumatic	64.4, n=90	73.2, n=41	56.3, n=16	69.9, n=83	76.9, n=39	81.8, n=11
	Non-Traumatic	81.5, n=27	70, n=10	81.5, n=27	81.5, n=27	70, n=10	100, n=22

Abbreviations: MSKP, Musculoskeletal Pain; LBP, Low Back Pain

Table 9.a.3.3: Presence of the pain categories, within each national group, divided by level of injury

		Total group			Only people with pain		
		USA %	UK %	GR %	USA %	UK %	GR %
Pain in general	Tetraplegia	89.1, n=64	91.7, n=24	73.3, n=15	n/a	n/a	n/a
	Paraplegia	100, n=58	100, n=28	80, n=30			
MSKP	Tetraplegia	30.2, n=63	33.3, n=24	46.2, n=13	33.9, n=56	36.4, n=22	66.7, n=9
	Paraplegia	43.9, n=57	50, n=28	37.9, n=29	43.9, n=57	50, n=28	47.8, n=23
Back pain	Tetraplegia	68.3, n=63	62.5, n=24	69.2, n=13	76.8, n=56	68.2, n=22	100, n=9
	Paraplegia	87.7, n=57	89.3, n=28	79.3, n=29	87.7, n=57	89.3, n=28	100, n=23
LBP lifetime	Tetraplegia	62.5, n=64	62.5, n=24	60, n=15	70.2, n=57	68.2, n=22	81.8, n=11
	Paraplegia	84.5, n=58	85.7, n=28	80, n=30	84.5, n=58	85.7, n=28	100, n=24
LBP current	Tetraplegia	55.7, n=61	60.9, n=23	57.1, n=14	63, n=54	66.7, n=21	80, n=10
	Paraplegia	76.8, n=56	78.6, n=28	75.9, n=29	76.8, n=56	78.6, n=28	95.7, n=23
LBP over 1 month	Tetraplegia	58.1, n=62	56.5, n=23	57.1, n=14	65.5, n=55	61.9, n=21	80, n=10
	Paraplegia	73.2, n=56	85.7, n=28	79.3, n=29	73.2, n=56	85.7, n=28	100, n=23
LBP over 3 months	Tetraplegia	58.1, n=62	56.5, n=23	57.1, n=14	65.5, n=55	61.9, n=21	80, n=10
	Paraplegia	80, n=55	85.7, n=28	79.3, n=29	80, n=55	85.7, n=28	100, n=23

Abbreviations: MSKP, Musculoskeletal Pain; LBP, Low Back Pain

Table 9.a.3.4: Two-group differences between national groups differences in the proportion of pain reported by males and females

		Greece	
		Males	**Female**
USA	Male	Fisher's, p≤0.01* n=104	
	Females		Fisher's, p=0.57 n=59
UK	Males	Fisher's, p=0.03* n=53	
	Females		Fisher's, p=0.57 n=40

*Significant at p≤0.05 level;
Statistical test: Fisher's exact

Table 9.a.3.5: Two-group differences between national groups differences in the proportion of pain reported by people divided into groups by cause of injury

		Greece	
		Traumatic	Non traumatic
USA	Traumatic	Fisher's, p=0.02* n=113	
	Non traumatic		Fisher's, p=0.01* n=54
UK	Traumatic	Fisher's, p=0.02* n=60	
	Non traumatic		Fisher's, p=0.29 n=37

*Significant at p≤0.05 level;
Statistical test: Fisher's exact

Table 9.a.3.6: Two-group differences, between national groups, in the proportion of pain reported by people divided into groups by level of injury

		Greece	
		Tetraplegia	**Paraplegia**
UK	Tetraplegia	Fisher's, p=0.180 n=39	
	Paraplegia		Fisher's, p=0.024* n=58
USA	Tetraplegia	Fisher's, p=0.20 n=79	
	Paraplegia		Fisher's, p≤0.001* n=88

*Significant at p≤0.05 level, ***Significant at p≤0.001 level;
Statistical test: Fisher's exact

Table 9.a.3.7: Percentage of category of pain, within each national group, reported by people divided in groups by level of injury

	USA Total n, %		UK Total n, %		GR Total n %	
Pain in general	Cervical n=64	89.1	Cervical n=24	91.7	Cervical n=15	73.3
	Thoracic n=38	100	Thoracic n=19	100	Thoracic n=16	68.8
	Lumbar n=20	100	Lumbar n=9	100	Lumbar n=14	92.9
MSKP	Cervical n=63	30.2	Cervical n=24	33.3	Cervical n=13	46.2
	Thoracic n=38	13.9	Thoracic n=19	52.6	Thoracic n=15	6.7
	Lumbar n=19	47.4	Lumbar n=9	44.4	Lumbar n=14	71.4
Back pain	Cervical n=63	61.9	Cervical n=24	62.5	Cervical n=13	69.2
	Thoracic n=38	81.6	Thoracic n=19	84.2	Thoracic n=15	66.7
	Lumbar n=19	94.7	Lumbar n=9	88.9	Lumbar n=14	92.9
LBP lifetime	Cervical n=64	62.5	Cervical n=24	62.5	Cervical n=15	60
	Thoracic n=38	78.9	Thoracic n=19	84.2	Thoracic n=16	68.8
	Lumbar n=20	95	Lumbar n=9	88.9	Lumbar n=14	92.9
LBP current	Cervical n=61	57.7	Cervical n=23	60.9	Cervical n=13	53.8
	Thoracic n=38	78.9	Thoracic n=19	73.7	Thoracic n=16	68.8
	Lumbar n=18	72.2	Lumbar n=9	88.9	Lumbar n=14	85.7
LBP over 1 month	Cervical n=62	58.1	Cervical n=23	56.5	Cervical n=14	57.1
	Thoracic n=38	73.7	Thoracic n=19	84.2	Thoracic n=15	66.7
	Lumbar n=18	72.2	Lumbar n=9	88.9	Lumbar n=14	92.9
LBP over 3 months	Cervical n=60	56.7	Cervical n=23	56.5	Cervical n=14	57.1
	Thoracic n=38	78.9	Thoracic n=19	84.2	Thoracic n=15	66.7
	Lumbar n=17	82.4	Lumbar n=9	88.9	Lumbar n=14	87.5

It is found that the lower the level of injury the higher the percentage of the pain categories reported across nations. There seems to be a wided differences in the reported cases of MSKP, between Greeks with different levels of injury. Indeed a significant difference was foundwithin the Greek group (Table 9.a.3.8).

Abbreviations: MSKP, Musculoskeletal Pain; LBP, Low Back Pain

Table 9.a.3.8: Within national group differences in the proportion of MSKP in groups divided by level of injury

	Statistical Tests	Cervical and Thoracic	Cervical and Lumbar	Thoracic and Lumbar
UK	p=0.44, χ^2=2.57, df2			
USA	p=0.22, χ^2=1.638, df2			
Greece	**p=0.002****	Fisher's exact	p=0.182	**p≤0.001*****
	χ^2=12.85, df2	p=0.029	χ^2=1.78, df1	χ^2=12.9, df1

**Significant at p≤0.01 level, ***Significant at p≤0.001 level,

in bold: remained significant following application of the Bonferroni correction;

Abbreviations: MSKP, Musculoskeletal Pain.

Statistical Tests: χ^2=,Independent Chi-square

Table 9.a.3.9: Mean age of people with and without the presence of pain across nations

		Total group							
		USA mean±SD min-max, n	**UK** mean±SD min-max, n	**GR** mean±SD min-max, n			**USA** mean±SD min-max, n	**UK** mean±SD min-max, n	**GR** **mean±SD min-max, n**
Pain in general	Yes	45.8±10.8 19.8-66.8, n=109	50.7±13.1 26.1-73.2, n=48	62.6±18.1 26.5-91.7, n=35	**LBP current**	Yes	45.9±10.5 19.8-40.7, n=73	49.2±13.8 26.1-73.2, n=36	66.3±15.3 30.9-91.7, n=29[1]
	No	41.9±10.4 29.3-59.3, n=7	54.2±15.1 43.5-64.9, n=2	59.5±15.8 37.5-79.7, n=10		No	45.1±11.4 26.9-66.8, n=38	55.3±10.0 39.1-70, n=13	56.7±15.6 37.5-80.2, n=13
MSKP	Yes	46.4±10.2 23.0-66.8, n=42	45.7±13.1 26.1-62.2, n=22	71.3±15.1 38.4-91.7, n=17[2]	**LBP over 1 month**	Yes	46.1±10.5 19.8-60.5, n=74	49.4±13.7 26.1-73.2, n=37	68.1±13.9 37.6-91.7, n=29
	No	43.3±111.1 19.8-65.3, n=72	56.0±10.4 36.3-73.2, n=27[1]	61.4±12.8 37.5-81.1, n=23		No	45.1±11.4 26.9-66.8, n=38	55.2±10.3 39.1-70, n=12	57.9±15.0 37.5-79.9, n=12[2]
Back pain	Yes	45.4±10.4 19.8-60.5, n=88	49.5±13.4 26.1-73.2, n=40	67.6±13.8 37.6-91.7, n=30	**LBP over 3 months**	Yes	45.6±10.5 19.8-60.5, n=76	49.4±13.7 26.1-73.2, n=37	68.0±13.9 37.6-91.7, n=29
	No	46.8±41.9 26.9-66.8, n=26	54.5±11.7 39.1-70, n=10	59.5±15.6 37.5-79.9, n=10		No	46.0±11.5 26.9-66.8, n=36	55.2±10.3 39.1-70, n=12	57.9±15.0 37.5-79.9, n=12
LBP lifetime	Yes	45.3±10.3 19.8-60.5, n=84	49.6±13.4 26.1-73.2, n=39	64.9±17.3 29.9-91.7, n=32[1]					
	No	46.2±11.9 26.9-66.8, n=32	55.2±10.8 39.1-70, n=11	57.9±37.5 37.5-79.9, n=12					

[1]One outlier eliminated, [2]Two outliers eliminated. When people without pain in general were excluded from this table the mean, SD, and range of the reported categories of pain did not change; Abbreviations: MSKP, Musculoskeletal Pain; LBP, Low Back Pain; SD, Standard Deviation

Table 9.a.3.10: Mean time since injury of people with and without presence of pain across nations

		Total group						
		USA mean±SD min-max, n	**UK** mean±SD min-max, n	**GR** mean±SD min-max, n			**USA** mean±SD min-max, n	**UK** mean±SD min-max, n	**GR** mean±SD min-max, n
Pain in general	Yes	9.7±9.4 0.3-35.8, n=110[3]	13.4±11.9 0.9-43.8, n=50	11.6±8.8 1.4-34.3, n=35	**LBP current**	Yes	9.9±10.2 0.3-35.8, n=74	14.0±12.0 0.9-43.8, n=36	11.1±8.1 1.4-31.0, n=30
	No	7.1±5.8 1.6-16.9, n=6[1]	25.3±2.9 23.2-27.4, n=2	8.8±4.3 1.5-14.1, n=10		No	10.1±8.3 0.5-29.7, n=38	13.8±10.1 1.1-28.4, n=15	11.4±8.6 1.5-34.3, n=13
MSKP	Yes	11.0±9.3 0.3-35.6, n=43[1]	13.5±11.8 0.9-43.2, n=22	13.8±9.3 2.4-34.3, n=17	**LBP over 1 month**	Yes	10.0±10.1 0.3-35.8, n=74[2]	14.3±13.0 0.9-43.8, n=37	10.8±8.1 1.4-31.0, n=31
	No	8.8±9.0 0.3-31.9, n=71[3]	14.5±12.0 0.9-43.8, n=29	8.5±5.1 1.4-20.7, n=22[1]		No	9.6±8.3 0.5-29.7, n=39[2]	13.0±9.3 1.1-27.4, n=14	11.9±8.8 1.5-34.3, n=12
Back pain	Yes	9.9±9.6 0.-35.8, n=89[1]	13.7±12.6 0.9-43.8, n=40	11.6±8.9 1.4-34.3, n=32	**LBP over 3 months**	Yes	9.5±9.6 0.3-35.8, n=77[2]	14.3±13.0 0.9-43.0, n=37	10.8±8.1 1.4-31.0, n=31
	No	9.7±9.9 0.4-29.7, n=26	14.1±9.6 1.1-27.4, n=12	10.5±2.3 7.6-14.1, n=8[1]		No	12.4±11.3 0.5-41.7, n=37	13.0±9.3 1.1-27.4, n=14	11.9±8.8 1.5-34.3, n=31
LBP lifetime	Yes	9.8±9.8 0.3-35.8, n=85[2]	13.9±12.7 0.9-43.8, n=39[1]	10.0±7.1 1.4-26.0, n=32					
	No	9.6±8.4 0.5-29.7, n=32[1]	13.6±27.4 1.1-27.4, n=13	11.9±8.8 1.5-34.3, n=12					

[1]One outlier eliminated, [2]Two outliers eliminated, [3]Four outliers eliminated. Abbreviations: MSKP, Musculoskeletal Pain; LBP, Low Back Pain; SD, Standard Deviation

Table 9.a.3.11: Two-group differences in the time since injury in groups divided by the presence of the pain categories

		UK	UK
		Yes (pain category)	**No** (pain category)
USA	Pain in general	t=-1.3, df162, p=0.19 95% CI -6.2, 1.2	t=-1.99, df7, p=0.08 95% CI -32.6, 2.7
	Back pain	t=-1.26, df130, p=0.20 95% CI -7.1, 1.5	t=-0.88, df37, p=0.3 95% CI -10.5, 4.1
	MSKP	t=-0.67, df64, p=0.5 95% CI -7.4, 3.7	t=-1.55, df102, p=0.1 95% CI -8.9, 1.0
	LBP lifetime	t=-1.3, df135, p=0.19 95% CI -7.4, 1.5	t=-0.95, df44, p=0.34 95% CI -9.5, 3.3
	LBP current	t=-1.3, df110, p=0.18 95% CI -7.9, 1.5	t=-0.70, df53, p=0.48 95% CI -8.4, 4.0
	LBP last 1 month	t=-1.4, df111, p=0.16 95% CI -8.0, 1.3	t=-0.60, df53, p=0.54 95% CI -8.2, 4.4
	LBP last 3 months	t=-2.1, df112, p=0.03* 95% CI -9.0, -0.4	t=-0.17, df49, p=0.86 95% CI -7.4, 6.2
Greece	Pain in general	U=8.63 , p=0.91	U=0.00 , p=0.03*
	Back pain	t=-0.07, df37, p=0.93 95% CI -7.3, 6.8	U=48.0 p=0.42
	MSKP	U=624.0 p=0.85	t=2.04, df52, p=0.04* 95% CI -17.6, 7.8
	LBP lifetime	U=605.0 P=0.66	t=0.47, df23, p=0.64 95% CI -5.8, 9.2
	LBP current	U=521.0 p=0.8	t=0.67, df26, p=0.5 95% CI -4.9, 9.7
	LBP last 1 month	U=536.0 p=0.64	t=0.31, df24, p=0.75 95% CI -6.2, 8.0
	LBP last 3 months	U=536.0 p=0.64	t=0.31, df24, p=0.75 95% CI -6.2, 8.4

*Significant at p≤0.05 level;
Abbreviations: MSKP, Musculoskeletal Pain; LBP, Low Back Pain;
Statistical tests: t, Independent t-test; U, Mann-Whitney U Test

9.a.4. Pain and LBP: relation to pain/LBP days, free periods, onset

Table 9.a.4.1: Percentage of people reporting the number of pain and LBP days felt per month across nations

Average pain days per month	Pain in general %			LBP %		
	UK n=50	USA n=113	Greece n=32	UK n=37	USA n=87	Greece n=32
1-9 days per month	8.0	10.6	37.5	21.6	24.1	37.5
10-20 days per month	6.0	14.2	28.1	8.1	17.2	31.3
21-30 days per month	8.0	9.7	12.5	10.8	10.3	15.6
Have pain every day	78	65.5	21.9	59.5	48.3	15.6

Abbreviation: LBP, Low Back Pain

Table 9.a.4.2: Percentage of people reporting the number of pain days felt per month, within each national group, divided in groups by the presence of MSKP

Average pain days per month	USA with MSKP (%)	USA no MSKP (%)	UK with MSKP (%)	UK no MSKP (%)	Greece with MSKP (%)	Greece no MSKP (%)
1-9 days per month	42.9	57.1	9.5	0	18.8	57.1
10-20 days per month	36.4	63.6	4.8	0	43.8	7.1
21-30 days per month	30	70	9.5	6.3	12.5	14.3
Have pain every day	49.1	50.9	76.2	93.8	25	21.4
Statistical Test	χ^2=1.7, df6 p=0.94, n=113		χ^2=4.8, df5 p=0.43, n=49		χ^2=10.6, df6 p=0.09, n=32	

Abbreviations: MSKP, Musculoskeletal Pain;
Statistical test: χ^2, Chi-Square

Table 9.a.4.3: Percentage of pain and LBP free weeks (since onset of pain/LBP) reported by people across nations

	Pain in general (%)			LBP (%)		
	UK n=48	**USA** n=105	**Greece** n=32	**UK** n=29	**USA** n=64	**Greece** n=30
Yes, most of the time	8.3	6.7	18.8	6.9	14.1	20
Yes frequently	4.2	8.6	21.9	6.9	0	23.3
Yes, sometimes	8.3	8.6	21.9	6.9	7.8	23.3
Yes, but not very often	6.3	2.9	21.9	6.9	4.7	20
Yes, but rarely	10.4	14.3	31	20.7	25	6.7
No, I always have pain	62.5	59	12.5	51.7	48.8	6.7

Abbreviation: LBP, Low Back Pain

Table 9.a.4.4: Percentage of people reporting onset of pain and LBP post iSCI across nations

Time of pain Onset	Pain in general (%)			LBP (%)		
	UK n=46	**USA** n=108	**Greece** n=33	**UK** n=34	**USA** n=77	**Greece** n=31
Immediately after iSCI	41.3	46.3	27.3	35.3	35.1	25.8
Within 1st month of iSCI	21.7	19.4	15.2	17.6	14.3	16.1
Between 1-6 months of iSCI	13.0	17.6	39.4	8.8	19.5	29.0
Between 6 months & 1 year of iSCI	8.7	4.6	9.1	2.9	9.1	19.4
After 1 year of iSCI	15.2	12	9.1	35.3	22.1	9.7

Abbreviation: iSCI, incomplete Spinal Cord Injury; LBP, Low Back Pain

Table 9.a.4.5: Differences in LBP onset post iSCI per cause of injury of groups from the three countries

	Onset immediately after iSCI	Statistical Test	Onset any other time post iSCI	Statistical Test
USA Traumatic	27.6%, n=16	χ^2=0.92	72.4%, n=42	χ^2=23.1
Non-traumatic	57.9%, n=11	p=0.33	42.1%, n=8	**p≤0.001*** **
UK Traumatic	37%, n=10	χ^2=5.33	63%, n=17	χ^2=6.54
Non-traumatic	28.6, n=2	p=0.02[1]	71.4%, n=5	**p=0.0011****
Greece Traumatic	10%, n=1	χ^2=4.500	33%, n=9	χ^2=1.08
Non-traumatic	90%, n=7	p=0.03[1]	66.7%, n=14	p=0.29

[1]not significant post Bonferroni correction; **Significant at p≤0.01 level, ***Significant at p≤0.001 level; **in bold:** significant following application of the Bonferroni correction;
Abbreviation: iSCI, incomplete Spinal Cord Injury.
Statistical test: χ^2, Chi-Square.

9.b. Pain extent and LBP experience across nations

9.b.1. Bonferroni Correction

Table 9.b.1.1: Main variables used in analysis of MPQ for cross-national and alpha value set following Bonferroni correction

Main Variables	Each main variable tested with the following variables		Alpha value following Bonferroni correction
S-PRI A-PRI T-PRI Intensity of current LBP Intensity of LBP over 1 month Intensity of LBP over 3 months PPI of LBP	1) Country 2) Gender 3) Cause of injury 4) Age 5) Type of injury 6) Time since injury 7) With age 8) Areas with pain	9) Pain days 10) LBP days 11) Pain free weeks 12) LBP free weeks 13) Pain onset 14) LBP onset	0.05/14=0.0035 p≤0.0035

Abbreviations: EQ-5D index, Quality of Life index; EQ-VAS, Quality of Life Visual Analogue Scale; MSKP, Musculoskeletal Pain; LBP, Low Back Pain; PRI, Present Rating Index

9.b.2. Pain extent; general results

Table 9.b.2.1: Mean number of areas with pain across nations. Difference in the number of areas with pain between nations

Areas of pain on the body	USA (%)	UK (%)	GR (%)	Between countries differences Extended χ^2, p value n=190
Head	2.7 n=3	2.1 n=1	3.1 n=1	χ^2=0.09, df2, p=0.95
Neck & shoulder	38.2 n=44	43.8 n=21	21.9 n=7	χ^2=4.15, df2, p=0.12
Upper extremities	16.4 n=18	31.3 n=15	9.4 n=3	χ^2=7.11, df2,p=0.02[1]
Frontal torso & genitals	28.2 n=31	29.2 n=14	3.1 n=1	χ^2=9.43, df2, p=0.09
Upper back	18.2 n=20	12.5 n=6	28.1 n=9	χ^2=3.12, df2, p=0.20
Lower back	76.4 n=84	79.2 n=38	93.8 n=30	χ^2=4.7, df2, p=0.09
Buttocks	47.3 n=52	47.9 n=23	46.9 n=15	χ^2=0.009, df2,p=0.99
Thighs	51.8 n=57	60.4 n=29	68.6 n=22	χ^2=3.23, df2, p=0.19
Legs & feet	49.1 n=54	64.6 n=31	43.8 n=14	χ^2=4.29, df2, p=0.11
Mean, median of total 9 areas	Mean 3.29 Median 3	Mean 3.71 Median 4	Mean 3.19 Median 3	χ^2=4.07, df2, p=0.13

[1]not significant post Bonferroni correction; *Statistical tests*: χ^2, extended Chi-Square

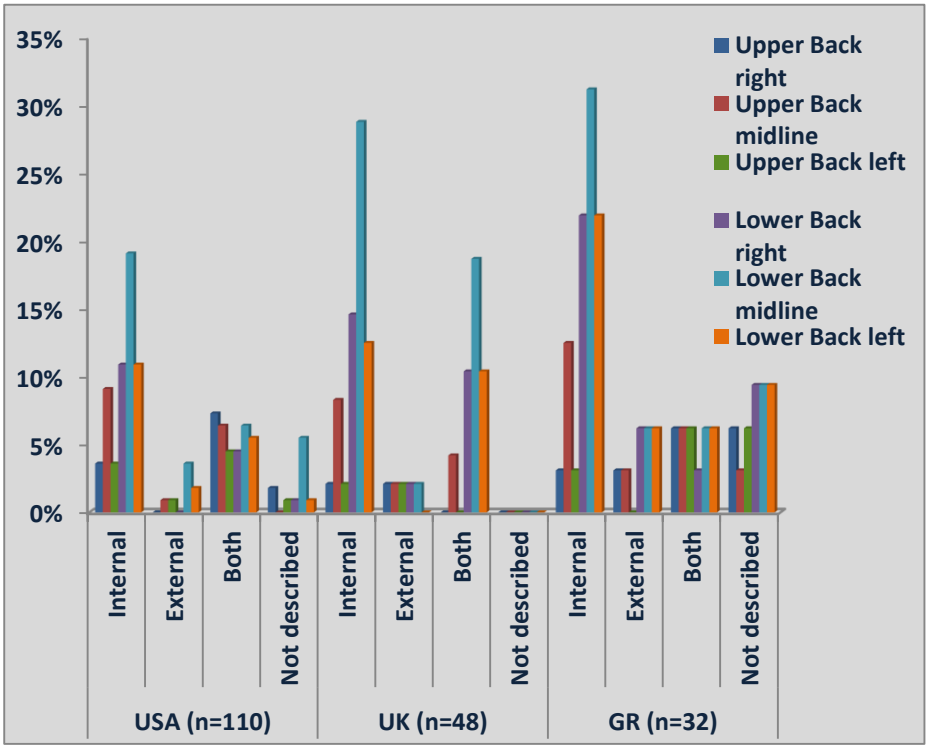

Figure 9.b.2.1: Description of pain at the back area reported across nations

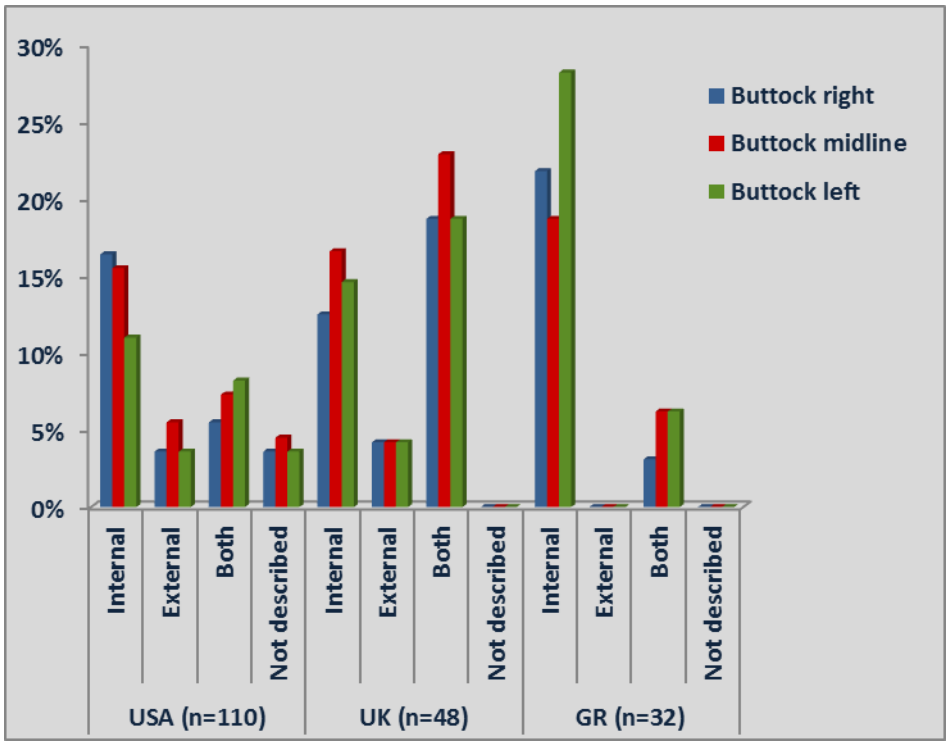

Figure 9.b.2.2: Description of pain at the buttocks reported across nations

9.b.3. Pain extent; relation to LBP and MSKP

Table 9.b.3.1: Mean number of areas with pain, within each national group, divided in groups by the presence of LBP or MSKP

	USA		UK		Greece	
	Yes mean±S min-max	**No** mean±SD min-max	**Yes** mean±SD min-max	**No** mean±SD min-max	**Yes** mean±SD min-max	**No** mean±SD min-max
Lifetime LBP	3.8±1.7 1-9, n=84	1.6±0.7 1-3, n=26	3.9±1.5 1-7, n=38	2.8±1.1 1-5, n=10[1]	3.6±1.7 2-9, n=16[1]	2.6±1.1 1-4, n=14
Current LBP	3.8±1.8 1-9, n=75	1.7±1.1 1-6, n=29	3.9±1.6 1-7, n=35	2.9±1.1 1-5, n=12	3.3±1.6 1-9, n=30[1]	2.0±1.4 1-3, n=2
LBP presence over last 1 month	3.8±1.8 1-9, n=75	2.1±1.4 1-6, n=34	3.9±1.5 1-7, n=36	2.6±0.8 1-4, n=10[1]	3.1±1.2 1-6,n=28	2.3±1.1 1-3, n=3
LBP presence over last 3 months	3.8±1.8 1-9, n=76	1.8±1.3 1-6, n=29[1]	3.9±1.5 1-7,n=36	2.6±0.8 1-4, n=10[1]	3.1±1.2 1-6, n=29[1]	2.0±1.4 1-3, n=2
MSKP	4.0±1.8 1-8, n=43[1]	2.6±1.4 1-7, n=65[1]	4.2±1.8 1-7, n=22	3.2±1.1 1-5, n=25	3.1±1.2 1-6, n=29[1]	2.0±1.4 1-3, n=2

[1]One outlier eliminated

Abbreviations: MSKP, Musculoskeletal Pain; LBP, Low Back Pain; SD, Standard Deviation

9.b.4. Pain extent; relation to demographic profile characteristics

Table 9.b.4.1: Summary of statistical differences in the number of areas with pain, within national groups, divided by demographic profile characteristics

	USA	UK	Greece
	Statistical Tests	Statistical Tests	Statistical Tests
Gender Male Female	U=776 p=0.02[1] 95% CI -1.32, -0.40	U=196 p=0.06	U=99.5 p=0.57
Cause of Injury Traumatic Non traumatic	t=-2.5, df106 p≤0.01[1] 95% CI -1.6, 0.1	U=174 p=0.67	U=104.5 p=0.98
Age	r=0.01 p=0.88, n=104	r=-0.29 p=0.04[1], n=46	ρ=0.24 p=0.16, n=32
Type of injury Tetraplegia Paraplegia	t=-0.78 p=0.43, df105 95% CI -0.8, 0.37	U=249 p=0.50	U=90 p=0.55
Time since injury	r=0.04 p=0.68, n=109	ρ=0.34 p≤0.01[1], n=48	ρ=0.05 p=0.75, n=32

[1]not significant post Bonferroni correction;

Statistical tests: U, Mann-Whitney U test; t, Independent t-test; r, Pearson's correlation; P, Spearman's rank correlation rho

Table 9.b.4.2: Mean number of areas with pain, within each national group, divided by demographic profile characteristics

		USA mean±S	**UK** mean±S	**Greece** mean±SD
Gender	Male	2.8±1.4 n=75[1]	3.3±1.5 n=27	3.5±2.2 n=15
	Female	4.0±1.9 n=33[1]	4.2±1.5 n=21	2.9±0.8 n=15
Cause of Injury	Traumatic	3.0±1.5 n=81	3.7±1.4 n=38	3.0±1.4 n=10
	Non Traumatic	3.9±2.0 n=27	3.6±1.9 n=10	3.0±1.1 n=21[1]
Type of injury	Tetraplegia	3.0±1.7 n=542[2]	3.5±1.6 n=20	3.8±2.6 n=9
	Paraplegia	3.3±1.5 n=53[2]	3.8±1.4 n=28	3.0±1.0 n=23

[1]One outlier eliminated, [2]Two outliers eliminated;
Abbreviations: SD, Standard Deviation

Table 9.b.4.3: Mean number of areas with pain, within each national group, divided by gender

	USA Males		USA Females		UK Males		UK Females		Greece Males		Greece Females	
	Yes mean±SD median min-max	**No** mean±SD median min-max	**Yes** mean±SD median min-max	**No** mean±SD median min-max	**Yes** mean±SD median min-max	**No** mean±SD median min-max	**Yes** mean±SD median min-max	**No** mean±SD median min-max	**Yes** mean±SD median min-max	**No** mean±SD median min-max	**Yes** mean±SD median min-max	**No** mean±SD median min-max
LBP lifetime	3.4±1.5 3, 1-9 n=57	3.4±1.5 3, 1-9 n=57	4.8±1.8 5, 2-9 n=27	1.9±0.9 2, 1-3 n=7	3.5±1.5 3.5, 1-6 n=20	2.7±1.4 2, 1-5 n=7	4.4±1.5 4.5, 2-7 n=18	3.00±0 n=3	3.7±2.2 3, 1-9 n=13	2.0±1.4 1-3, n=2	4.5±1.5 5, 4.5-1.5, n=17	n/a n=0
LBP current	3.4±1.5 3, 1-9 n=51	1.8±1.2 3, 1-6 n=23	4.7±1.9 4.5, 2-9 n=24	2.6±1.7 2, 1-6 n=9	3.4±1.5 3, 1-6 n=18	2.9±1.3 2.5, 1-5 n=8	4.5±1.5 5, 2-7 n=17	3.00±0 n=4	3.7±2.2 3, 1-9 n=13	2.0±1.4 2, 1-3 n=2	2.9±0.9 3, 1-4 n=14	n/a n=1
LBP over 1 month	3.4±1.5 3, 1-9 n=51	1.8±1.2 1.5, 1-6 n=24	4.7±1.9 4.5, 2-9 n=24	2.8±1.7 2.5, 1-6 n=57	3.5±1.5 3.5, 1-6 n=18	2.7±1.3 2.5, 1-5 n=8	4.4±1.5 4.5, 2-7 n=18	3.00±0 n=3	3.7±2.2 3, 1-9 n=13	2.0±1.4 2, 1-3 n=2	2.9±0.8 3, 1-4 n=15	n/a n=0
LBP over 3 months	3.3±1.5 3, 1-9 n=51	1.8±1.2 1.5, 1-6 n=22	4.8±1.9 5, 2-9 n=25	2.4±1.7 2, 1-6 n=8	3.5±1.5 3.5, 1-6 n=18	2.7±1.3 2.5, 1-5 n=8	4.4±1.5 4.5, 2-7 n=18	3.00±0 n=3	3.7±2.2 3, 1-9 n=13	2.0±1.4 2, 1-3 n=2	2.9±0.8 3, 1-4 n=15	n/a n=0

Abbreviations: LBP, Low Back Pain; SD, Standard Deviation

Table 9.b.4.4: Differences in the number of areas with pain within males or females with and without LBP

	USA Between Males	USA Between females
Lifetime LBP	χ^2=0.16, p=0.68	χ^2=1.47, p=0.22
Current LBP	χ^2=0.39, p=0.52	χ^2=2.13, p=0.14
LBP over last 1 month	χ^2=0.65, p=0.41	χ^2=4.26, p=0.03*
LBP over last 3 months	χ^2=0.35, p=0.55	χ^2=2.7, p=0.1

*significant at p≤0.05 level;
Abbreviations: LBP, Low Back Pain;
Statistical test: χ^2, Goodness of fit chi-Square

9.b.5. Pain extent; relation to pain/LBP days, free periods, onset

Table 9.b.5.1: Correlations between the number of areas with pain and the number of pain or LBP days felt per month within each national group

	USA	UK	Greece
Areas with pain and pain days	ρ=0.32 **p=0.001*****, n=110	ρ=0.05 p=0.71, n=48	ρ=0.20 p=0.26, n=31
Areas with pain and LBP days	ρ=0.20 p=0.06, n=79	ρ=0.12 p=0.48, n=34	ρ=0.32 p=0.08, n=29

***significant at p≤0.001 level;
Abbreviations: LBP, Low Back Pain;
Statistical test: ρ, Spearman's rank correlation rho

Table 9.b.5.2: Correlations between the number of areas with pain and the frequency of pain or LBP free weeks within each national group

Correlation between	USA	UK	Greece
Areas with pain and pain free weeks	ρ=0.16 p=0.11, n=101	ρ=0.26 p=0.07, n=46	ρ=-0.05 p=0.77, n=31
Areas with pain and LBP free weeks	ρ=0.009 p=0.94, n=61	ρ=0.21 p=0.26, n=44	ρ=0.10 p=0.57, n=29

Abbreviations: LBP, Low Back Pain;
Statistical test: ρ, Spearman's rank correlation rho

9.b.6. LBP quality and intensity; relation to demographic profile characteristics

Table 9.b.6.1: Differences in the LBP quality or intensity between gender, within each national group. Interaction effect between country of residence and gender on LBP quality or intensity

	Comparisons within each country			Effect of gender *country on DV
	USA	**UK**	**GR**	
S-PRI	t=-0.07, df81 p=0.94 95% CI -3.4, 3.1	t=0.58, df36 p=0.56 95% CI -4.3, 7.9	t=-0.04, df26 p=0.96 95% CI -3.3, 3.2	F=0.23, p=0.78 η^2=0.001 n=150
A-PRI	t=-0.68, df81 p=0.49 95% CI -2.1, 1.0	t=0.09, df36 p=0.92 95% CI -2.4, 2.6	t=1.73, df27 p=0.09 95% CI -0.36, 4.4	F=1.40, p=0.25 η^2=0.0093 n=150
Total PRI	t=-0.68, df81 p=0.49 95% CI -2.1, 1.0	t=0.09, df36 p=0.92 95% CI -2.4, 2.6	t=1.34, df26 p=0.19 95% CI -0.7, 3.5	F=0.84, p=0.43 η^2=0.0044 n=147
Intensity of current LBP	t=-0.20, df83 p=0.83 95% CI -14.0, 11.4	t=0.55, df34 p=0.58 95% CI-14.6, 2.5	n/a	F=0.71, p=0.49 η^2=0.0035 n=124
Intensity of LBP over last 1 month	t=-0.60, df83 p=0.54 95% CI-16.2, 8.6	t=-0.29, df32 p=0.77 95% CI -21.5, 16.1	n/a	F=0.84, p=0.43 η^2=0.0035 n=122
Intensity of LBP over last 3 months	t=-0.65, df82 p=0.51 95% CI-16.2, 8.1	t=-0.67, df35 p=0.50 95% CI -25.9, 13.1	n/a	F=1.13, p=0.32 η^2=0.0045 n=121
Evaluative PPI of LBP	t=-0.73, df76 p=0.46 95% CI -0.6, 0.2	t=-0.27, df30 p=0.78 95% CI -0.7, 0.5	t=1.07, df26 p=0.29 95% CI -0.2, 0.8	F=0.83, p=0.43 η^2=0.0016 n=139

Abbreviations: PRI, Pain Rating Index; S-PRI, Sensory PRI; A-PRI, Affective PRI; LBP, Low Back Pain; PPI, Present Pain Intensity

Statistical tests: t, Independent t-test; F, Two-way ANOVA

Table 9.b.6.2: Two-group comparisons, within each national group, for differences in LBP quality within gender

		UK					
		S-PRI		A-PRI		Total PRI	
		Male	Female	Male	Female	Male	Female
USA	Male	NT	NT	NT	NT	U=446.5 P=0.46	NT
	Female	NT	NT	NT	NT	NT	NT
Greece	Male	U=86 P=0.058	NT	NT	NT	U=99 P=0.20	NT
	Female	NT	U=94.5 P=0.14	NT	U=97.5 P=0.16	NT	U=98.5 P=0.27

Abbreviations: PRI, Present Rating Index; NT, Not Tested;
Statistical Test: U, Mann-Whitney U Test

Table 9.b.6.3: Differences, between the national groups, in LBP quality or intensity between groups divided by cause of injury. Interaction effect between country of residence and cause of injury on LBP quality or intensity

	Comparisons within each country			Effect of cause of injury *country on DV
	USA	**UK**	**GR**	
S-PRI	t=-1.70, df81, p=0.09 95% CI -6.4, 0.4	U=92.5 p=0.54	U=73.5 p=0.33	F=0.13, p=0.87 η^2=0.00061 n=152
A-PRI	t=-1.12, df81, p=0.26 95% CI -2.6, 0.7	U=107 p=0.95	U=79.5 p=0.48	F=0.41, p=0.66 η^2=0.0028 n=152
Total PRI	t=-1.94, df79, p=0.056 95% CI -9.1, 0.1	U=81 p=0.41	U=69.5 p=0.25	F=0.03, p=0.96 η^2=0.00018 n=149
Intensity of current LBP	t=-0.19, df83, p=0.80 95% CI -14.7, 12.1	U=89.5 p=0.63	n/a	F=0.12, p=0.88 η^2=0.00060 n=124
Intensity of LBP over last 1 month	t=-1.05, df83, p=0.29 95% CI -20.0, 6.1	U=75.5 p=0.70	n/a	F=0.05, p=0.94 η^2=0.00022 n=122
Intensity of LBP over last 3 months	t=-0.83, df81, p=0.40 95% CI -18.0, 7.3	U=64.5 p=0.37	n/a	F=0.08, p=0.92 η^2=0.00033 n=121
Evaluative PPI of LBP	t=-1.05, df76, p=0.29 95% CI -0.7, 0.2	U=969 p=0.53	U=72.5 p=0.28	F=0.16, p=0.85 η^2=0.00032 n=141

Abbreviations: PRI, Pain Rating Index; S-PRI, Sensory PRI; A-PRI, Affective PRI; LBP, Low Back Pain; PPI, Present Pain Intensity;
Statistical tests: U, Mann-Whitney U test; t, Independent t-test; F, Two-way ANOVA

Table 9.b.6.4: Two-group comparisons, within each national group, for differences in LBP quality in groups divided by cause of injury

Greece							
		S-PRI		A-PRI		Total PRI	
		Traumatic	Non traumatic	Traumatic	Non traumatic	Traumatic	Non traumatic
USA	Traumatic	U=154.5 **p=0.03***	NT	U=205.5 p=0.23	NT	U=161 p=0.058	NT
	Non traumatic	NT	U=145.5 **p≤0.01****	NT	U=199 p=0.20	NT	U=147 **p≤0.01****
UK	Traumatic	U=80.5 p=0.055	NT	NT	NT	U=81 p=0.08	NT
	Non traumatic	NT	U=33.5 **p=0.02***	NT	NT	NT	U=42.5 p=0.078

*significant at p≤0.05 level; **significant at p≤0.01 level;
in bold: significant following Bonferroni post hoc
Abbreviations: PRI, Present Rating Index; S-PRI, Sensory PRI; A-PRI; NT, Not Tested;
Statistical Test: U, Mann-Whitney U Test

Table 9.b.6.5: Two-group comparisons, between the national groups, for differences in LBP quality in groups divided by level of injury

Greece							
		S-PRI		A-PRI		Total PRI	
		Tetraplegia	Paraplegia	Tetraplegia	Paraplegia	Tetraplegia	Paraplegia
USA	Tetraplegia	U=141.5 p=0.76	NT	NT	NT	NT	NT
	Paraplegia	NT	U=241 **p≤0.001***	NT	U=355 **p=0.03***	NT	U=258 **p≤0.01****
UK	Tetraplegia	U=39.5 p=0.51	NT	NT	NT	U=38.5 p=0.46	NT
	Paraplegia	NT	U=148 **p=0.06***	NT	NT	NT	U=167.5 **p=0.003****

*significant at p≤0.05, **significant at p≤0.01; **in bold:** significant following Bonferroni post hoc; Abbreviations: PRI, Present Rating Index; S-PRI, Sensory PRI; A-PRI; NT, Not Tested;
Statistical Test: U, Mann-Whitney U Test

Table 9.b.6.6: Correlations, within each national group, between quality or intensity of LBP and age or time since injury

	Age of respondent			Time since injury		
	USA	**UK**	**GR**	**USA**	**UK**	**GR**
S-PRI	r=-0.004 p=0.97 n=79	r=-0.19 p=0.25 n=38	r=-0.30 p=0.09 n=31	r=0.08 p=0.44 n=82	r=-0.11 p=0.48 n=38	r=-0.14 p=0.43 n=31
A- PRI	r=0.07 p=0.51 n=79	r=-0.14 p=0.37 n=38	r=-0.32 p=0.07 n=31	r=0.02 p=0.81 n=82	r=0.10 p=0.54 n=38	r=-0.18 p=0.33 n=31
Total PRI	r=-0.02 p=0.85 n=78	r=-0.17 p=0.32 n=36	r=-0.33 p=0.07 n=31	r=0.09 p=0.38 n=81	r=0.24 p=0.15 n=36	r=-0.16 p=0.36 n=31
Intensity of current LBP	r=-0.001 p=0.99 n=80	r=-0.02 p=0.90 n=36	r=0.33 p=0.78 n=3	r=0.02 p=0.84 n=84	r=0.22 p=0.19 n=36	r=0.83 p=0.36 n=3
Intensity of LBP over last 1 month	r=0.15 p=0.16 n=80	r=-0.13 p=0.45 n=34	r=0.33 p=0.78 n=3	r=-0.07 p=0.50 n=84	r=0.40 p≤0.01[1] n=34	r=0.83 p=0.37 n=3
Intensity of LBP over last 3 months	r=0.13 p=0.24 n=80	r=-0.15 p=0.38 n=34	r=0.47 p=0.68 n=3	r=-0.20 p=0.058 n=83	r=0.34 p=0.04[1] n=34	r=0.90 p=0.27 n=3
Evaluative PPI of LBP	r=0.15 p=0.19 n=73	r=-0.22 p=0.21 n=33	r=0.02 p=0.91 n=30	r=0.07 p=0.51 n=77	r=-0.06 p=0.72 n=33	r=0.12 p=0.50 n=30

[1]not significant post Bonferroni correction;

Abbreviations: PRI, Pain Rating Index; LBP, Low Back Pain; PPI, Present Pain Intensity. *Statistical tests*: r, Pearson's correlation; ρ, Spearman's rank correlation rho

9.b.7 LBP quality and intensity; general results

Table 9.b.7.1: Percentage of used verbal descriptors to mark severity of LBP quality in groups across nations

Verbal descriptors	Reported pain total			None			Mild			Moderate			Severe		
UK; n=36 **USA**; n=83 **GR**; n=30	**UK**	**USA**	**GR**	**UK**	**USA**	**GR**	**UK**	**USA**	**GR**	**UK**	**USA**	**GR**	**UK**	**USA**	**GR**
Throbbing	50	44.6	20	50	55.4	80	19.4	14.5	16.7	5.6	21.7	0	2.5	8.4	3.3
Shooting	51.4	49.4	35.5	48.6	50.6	64.5	5.4	15.7	29	29.7	16.9	3.2	16.2	16.9	3.2
Stabbing	54.3	44.6	38.7	45.7	55.4	61.3	8.6	7.2	19.4	20	18.1	6.5	25.7	19.3	12.9
Sharp	55.6	50.6	61.3	44.4	49.4	38.7	8.3	12	25.8	27.8	19.3	19.4	19.4	19.3	16.2
Cramping	50	50.6	35.5	50	49.4	64.5	27.8	20.5	22.6	16.7	20.5	12.9	5.6	9.6	0
Gnawing	68.4	45.8	64.5	31.6	54.2	35.5	28.9	10.8	41.9	23.7	26.5	16.1	15.8	8.4	6.5
Hot-burning	59.5	52.4	50	40.5	47.6	50	13.5	15.9	33.3	16.2	25.6	6.7	29.7	11	10
Aching	86.5	84.3	41.9	13.5	15.7	58.1	18.9	18.1	19.4	27	48.2	16.1	40.5	18.1	6.5
Heavy	56.8	42.7	35.5	43.2	57.3	64.5	24.3	12.2	16.1	13.5	22	16.1	18.9	8.5	3.2
Tender	58.3	44.6	22.6	41.7	55.4	77.4	13.9	15.7	16.1	25	19.3	3.2	19.4	9.6	3.2
Splitting	38.9	30	19.4	61.1	70	80.6	8.3	17.5	9.7	25	5	6.5	5.6	7.5	3.2
Tiring-exhausting	64.9	65.1	48.4	35.1	34.9	51.6	10.8	15.7	12.9	21.6	28.9	25.8	32.4	20.5	9.7
Sickening	45.9	31.7	32.3	54.1	68.3	67.7	13.5	13.4	22.6	16.2	9.8	3.2	16.2	8.5	6.5
Fearful	31.6	29.3	35.5	68.4	70.7	64.5	13.2	11	22.6	10.5	12.2	3.2	7.9	6.1	9.7
Punishing-cruel	47.4	49.4	38.7	52.6	50.6	61.3	15.8	15.7	25.8	18.4	19.2	6.5	13.2	14.5	6.5

Table 9.b.7.2: Characteristics of LBP quality descriptors across national groups

Verbal descriptor	Median			Mean			SD			Skewness			Kurtosis			Sum		
UK; n=35-38 **USA**; n=82-83 **GR**; n=30-31	**UK**	**USA**	**GR**	**UK**	**USA**	**GR**	**UK**	**USA**	**GR**	**UK**	**USA**	**GR**	**UK**	**USA**	**GR**	**UK**	**USA**	**GR**
Throbbing	0.5	0	0	1.06	0.83	0.27	1.26	1.04	0.64	0.70	0.80	3.09	-1.24	-0.80	11.20	38	69	8
Shooting	1	0	0	1.14	1	9.45	1.20	1.16	0.72	0.33	0.65	1.87	-1.58	-1.14	4.06	42	83	14
Stabbing	1	0	0	1.26	1.01	0.71	1.29	1.23	1.07	0.27	0.61	1.32	-1.70	-1.34	0.40	44	84	22
Sharp	1	1	1	1.22	1.08	1.13	1.22	1.21	1.11	0.24	0.50	0.49	-1.61	-1.38	-1.12	44	90	35
Cramping	0.5	1	0	0.78	0.90	0.48	0.92	1.04	0.72	0.92	0.72	1.18	-0.14	-0.82	0.03	28	75	15
Gnawing	1	0	1	1.24	0.89	0.94	1.07	1.07	0.89	0.32	0.64	0.73	-1.14	-1.11	-1.03	47	74	29
Hot-burning	1	1	0.5	1.35	1	0.77	1.29	1.08	0.97	0.18	0.53	1.23	-1.72	-1.18	0.83	50	82	23
Aching	2	2	0	1.95	1.69	0.71	1.07	0.94	0.97	-0.59	-0.46	1.10	-0.94	-0.62	0.82	72	140	22
Heavy	1	0	0	1.08	0.82	0.58	1.16	1.05	0.88	0.61	0.82	1.27	-1.11	-0.81	0.44	40	67	18
Tender	1	0	0	1.22	0.83	0.32	1.19	1.05	0.70	0.28	0.85	2.54	-1.51	-0.70	6.85	44	69	10
Splitting	0	0	0	0.75	0.50	0.32	1.02	0.90	0.74	0.87	1.81	2.48	-0.80	2.27	5.4	27	40	10
Tiring-exhausting	2	1	0	1.51	1.35	0.94	1.28	1.16	1.09	-1.07	0.08	0.62	-1.72	-1.48	-1.13	56	112	29
Sickening	0	0	0	0.95	0.59	0.48	1.17	0.98	0.85	0.75	1.48	1.95	-1.04	0.86	3.42	35	48	15
Fearful	0	0	0	0.58	0.54	0.58	0.97	0.93	0.95	1.51	1.53	1.69	1.02	1.02	1.95	22	44	18
Punishing-cruel	0	0	0	0.92	0.98	0.58	1.12	1.13	0.88	0.76	0.61	1.58	-0.92	-1.09	1.89	35	81	18
Total S-PRI (0-33)	13	8	6	12.53	10.52	6.65	9.22	7.46	5.36	0.49	0.73	1.72	-0.71	-0.45	4.38	476	873	206
Total A-PRI (0-12)	3.5	2	2	3.89	3.43	2.58	3.84	3.48	3.29	0.69	0.89	1.59	-0.61	-0.23	2.07	148	285	80
Total PRI (0-45)	15.5	12	6	16.42	13.95	9.23	12.74	10.21	8.23	0.57	0.70	1.83						

Table 9.b.7.3: Mean LBP quality in groups across nations. Percentage of total or no usage of verbal descriptors

	Total PRI		**S-PRI**		**A-PRI**	
	mean±SD range	%	mean±SD range	%	mean±SD range	%
USA n=83	7.1±4.6 1-15	5.7% using all descriptors	5.4±3.4 1-11	8.2% using all descriptors	1.7±1.5 0-4	14.6% using all descriptors 19.7% using no descriptors
UK n=38	7.9±5.1 1-15	11.5% using all descriptors	6.06±3.8 0-11	13.5% using all descriptors 19% using no descriptor	1.9±1.6 0-4	15.4% using all descriptors 23.1%% using no descriptor
GR n=31	5.8±4.6 1-15	2.2 using all descriptors	4.2±3.2 0-11	2.2% using all descriptors 2.2% using no descriptors	1.5±1.6 0-4	13.3% using all descriptors 26.7% using no descriptors

Abbreviations: PRI, Pain Rating Index.
Statistical test: F, One-way ANOVA

9.b.8. LBP quality and intensity; relation to pain/LBP days, free periods, onset

Table 9.b.8.1: Correlation, within each national group, between the number of pain or LBP days and quality or intensity of LBP

	Pain days			LBP days		
	USA	**UK**	**Greece**	**USA**	**UK**	**Greece**
S-PRI	ρ=0.13 p=0.23 n=83	ρ=0.06 p=0.70 n=38	ρ=-0.21 p=0.23 n=31	ρ=0.43 **p≤0.001***** n=78	ρ=0.45 p=0.006[1] n=34	ρ=-0.13 p=0.48 n=30
A-PRI	ρ=0.08 p=0.46 n=83	ρ=0.04 p=0.78 n=38	ρ=-0.25 p=0.16 n=31	ρ=0.34 **p=0.002**** n=78	ρ=0.45 p=0.006[1] n=34	ρ=-0.14 p=0.44 n=30
Total PRI	ρ=0.11 p=0.30 n=82	ρ=0.01 p=0.95 n=36	ρ=-0.28 p=0.12 n=31	ρ=0.43 **p≤0.001****** n=77	ρ=0.44 p≤0.01[1] n=32	ρ=-0.16 p=0.37 n=30
Intensity of current LBP	ρ=0.25 p=0.02[1] n=85	ρ=0.36 p=0.03 n=36	ρ=0.86 p=0.33 n=3	ρ=0.53 **p≤0.001***** n=80	ρ=0.54 **p≤0.001***** n=32	n=2 n/a
Intensity of LBP over last 1 month	ρ=0.22 p=0.03[1] n=85	ρ=0.27 p=0.11 n=34	ρ=0.86 p=0.33 n=3	ρ=0.56 **p≤0.001***** n=80	ρ=0.45 p=0.01[1] n=30	n=2 n/a
Intensity of LBP over last 3 months	ρ=0.13 p=0.22 n=84	ρ=0.25 p=0.14 n=34	ρ=0.86 p=0.33 n=3	ρ=0.41 **p≤0.001***** n=79	ρ=0.54 **p=0.002**** n=30	n=2 n/a
Evaluative PPI of LBP	ρ=0.10 p=0.38 n=78	ρ=0.12 p=0.49 n=33	ρ=0.14 p=0.44 n=30	ρ=0.40 **p≤0.001***** n=75	ρ=0.49 p=0.006[1] n=30	ρ=0.28 p=0.13 n=28

[1]not significant post Bonferroni correction; **significant at p≤0.01 level, ***significant at p≤0.001 level; **In bold:** remained significant following application of the Bonferroni correction.
Abbreviations: PRI, Present Rating Index; LBP, Low Back Pain; PPI, Present Pain Intensity; *Statistical Test*: ρ, Spearman's rank correlation rho

Table 9.b.8.2: Correlation, within each national group, between the number of pain or LBP free weeks and quality or intensity of LBP

	Pain free weeks			LBP free weeks		
	USA	**UK**	**Greece**	**USA**	**UK**	**Greece**
S-PRI	ρ=0.19 p=0.09 n=77	ρ=0.27 p=0.10 n=36	ρ=-0.17 p=0.34 n=30	ρ=0.33 p≤0.01[1] n=60	ρ=0.41 p=0.02[1] n=29	ρ=-0.11 p=0.55 n=30
A-PRI	ρ=0.17 p=0.13 n=77	ρ=0.33 p=0.04[1] n=36	ρ=0.08 p=0.65 n=30	ρ=0.19 p=0.14 n=60	ρ=0.41 p=0.009[1] n=29	ρ=0.05 p=0.79 n=30
Total PRI	ρ=0.19 p=0.09 n=76	ρ=0.23 p=0.18 n=34	ρ=-0.10 p=0.59 n=30	ρ=0.28 p=0.02[1] n=59	ρ=0.39 p=0.03[1] n=28	ρ=-0.03 p=0.87 n=30
Intensity of current LBP	ρ=0.35 p=0.01[1] n=79	ρ=0.58 **p≤0.001**** n=34	ρ=1.000 n/a n=3	ρ=0.53 **p≤0.001***** n=61	ρ=0.53 p=0.004[1] n=27	ρ=1.000 n/a n=2
Intensity of LBP over last 1 month	ρ=0.33 **p=0.003**** n=85	ρ=0.35 p=0.04[1] n=32	ρ=1.000 n/a n=3	ρ=0.46 **p≤0.001***** n=61	ρ=0.65 **p≤0.001***** n=25	ρ=1.000 n/a n=2
Intensity of LBP over last 3 months	ρ=0.29 p=0.008[1] n=78	ρ=0.04 p=0.02[1] n=32	ρ=1.000 n/a n=3	ρ=0.34 p=0.007[1] n=60	ρ=0.71 **p≤0.001***** n=25	ρ=1.000 n/a n=2
Evaluative PPI of LBP	ρ=0.17 p=0.14 n=72	ρ=0.30 p=0.10 n=31	ρ=0.19 p=0.32 n=29	ρ=0.29 p=0.03[1] n=54	ρ=0.57 **p=0.003***** n=25	ρ=0.40 p=0.03[1] n=29

[1]not significant post Bonferroni correction; **significant at p≤0.01 level, ***significant at p≤0.001 level; **In bold:** remained significant following application of the Bonferroni correction.
Abbreviations: PRI, Present Rating Index; S-PRI, Sensory PRI; A-PRI; LBP, Low Back Pain; PPI, Present Pain Intensity;
Statistical Test: ρ, Spearman's rank correlation rho

Table 9.b.8.3: Correlations, within each national group, between the number of areas with pain and LBP quality or intensity. Interaction effect of country of residence and the number of areas with pain on LBP quality or intensity.

	USA	UK	GR	Effect of number of areas with pain *country on DV
S-PRI	r=0.27 p≤0.01[1] n=80	r=0.22 p=0.18 n=37	r=0.35 p=0.057 n=30	F=1.78, p=0.067 η^2=0.021 n=147
A-PRI	r=0.20 p=0.07 n=81	r=0.32 p=0.05[1] n=37	r=0.31 p=0.08 n=30	F=0.61, p=0.82 η^2=0.025 n=148
Total PRI	r=0.26 p≤0.01[1] n=80	r=0.30 p=0.07 n=35	r=0.35 p=0.0054 n=30	F=1.64, p=0.80 η^2=0.018 n=145
Intensity of current LBP	r=0.18 p=0.08 n=83	r=0.10 p=0.56 n=35	ρ=0.50 p=0.66 n=3	F=1.18, p=0.31 η^2=0.023 n=121
Intensity of LBP over last 1 month	r=0.12 p=0.24 n=83	r=0.15 p=0.39 n=33	ρ=0.50 p=0.66 n=3	F=1.14, p=0.33 η^2=0.019 n=119
Intensity of LBP over last 3 months	r=0.23 p=0.03[1] n=82	r=0.09 p=0.59 n=33	ρ=0.50 p=0.66 n=3	F=1.54, p≤0.01[1] η^2=0.15 n=118
Evaluative PPI of LBP	r=0.33 **p=0.003**** n=80	r=0.11 p=0.52 n=52	r=0.25 p=0.18 n=29	F=1.93, p=0.50 η^2=0.009 n=137

[1]not significant post Bonferroni correction; **significant at p≤0.01 level;
In bold: remained significant following application of the Bonferroni correction.
Abbreviations: PRI, Pain Rating Index; S-PRI, Sensory PRI; A-PRI; LBP, Low Back Pain; PPI, Present Pain Intensity;
Statistical tests: r, Pearson's correlation; F, Two-way ANOVA

9.c. Quality of life within and across nations

9.c.1. Bonferroni Correction

Table 9.c.1.1: Main variables used in analysis of EQ-5D for cross-national and alpha value set following Bonferroni correction

Main Variables	Each main variable tested with the following variables		Alpha value following Bonferroni correction
1) EQ-5D 2) EQ-VAS	1) Pain 2) LBP 3) MSKP 4) Country 5) Gender 6) Cause of injury 7) Age 8) Type of injury 9) Time since injury 10) Marital status 11) Education 12) Employment	13) Areas with pain 14) Pain days 15) LBP days 16) Pain free weeks 17) LBP free weeks 18) Pain onset 19) LBP onset 20) S-PRI of LBP 21) A-PRI of LBP 22) T-PRI of LBP 23) Intensity of current LBP 24) Intensity LBP last 1 month 25) Intensity LBP last 3 months 26) Evaluative PPI of LBP	0.05/26=0.002 p≤0.002

Abbreviations: EQ-5D index, Quality of Life index; EQ-VAS, Quality of Life Visual Analogue Scale; MSKP, Musculoskeletal Pain; LBP, Low Back Pain; PRI, Present Rating Index.

9.c.2. EQ-5D; relation to pain, MSKP and LBP

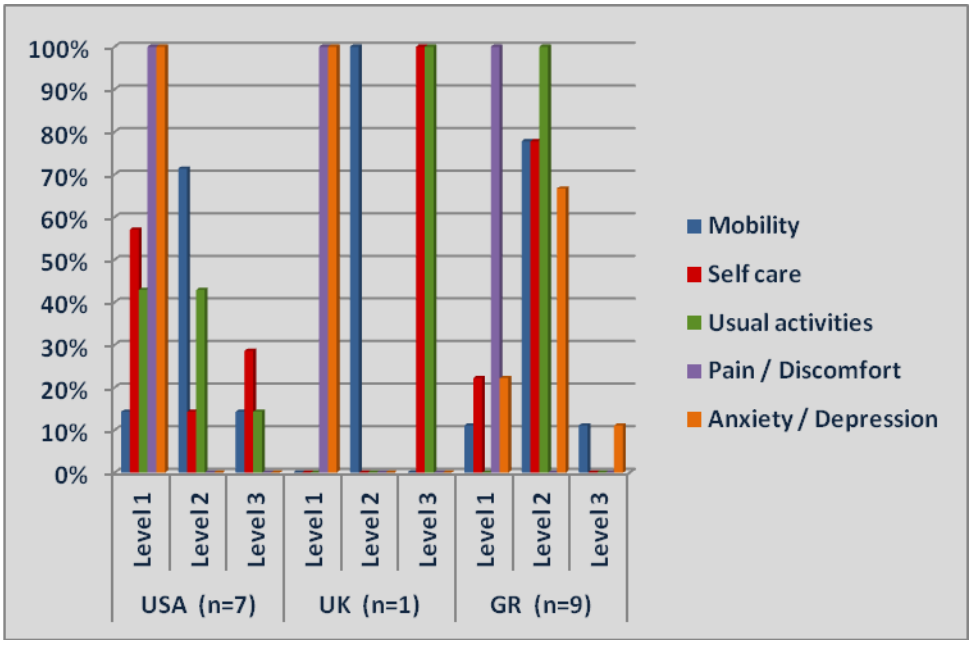

Figure 9.c.2.1: Percentage of people, within each national group, without pain reporting each health status dimension; Abbreviation: EQ-5D, Quality of Life

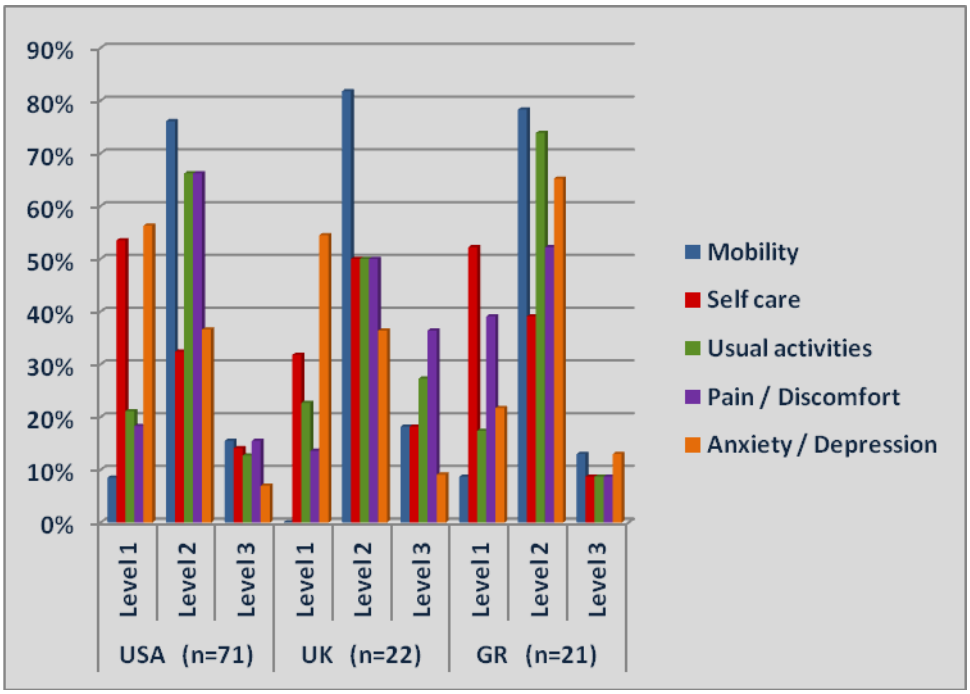

Figure 9.c.2.2: Percentage of people, within each national group, without MSKP reporting each health status dimension
Abbreviation: EQ-5D, Quality of Life

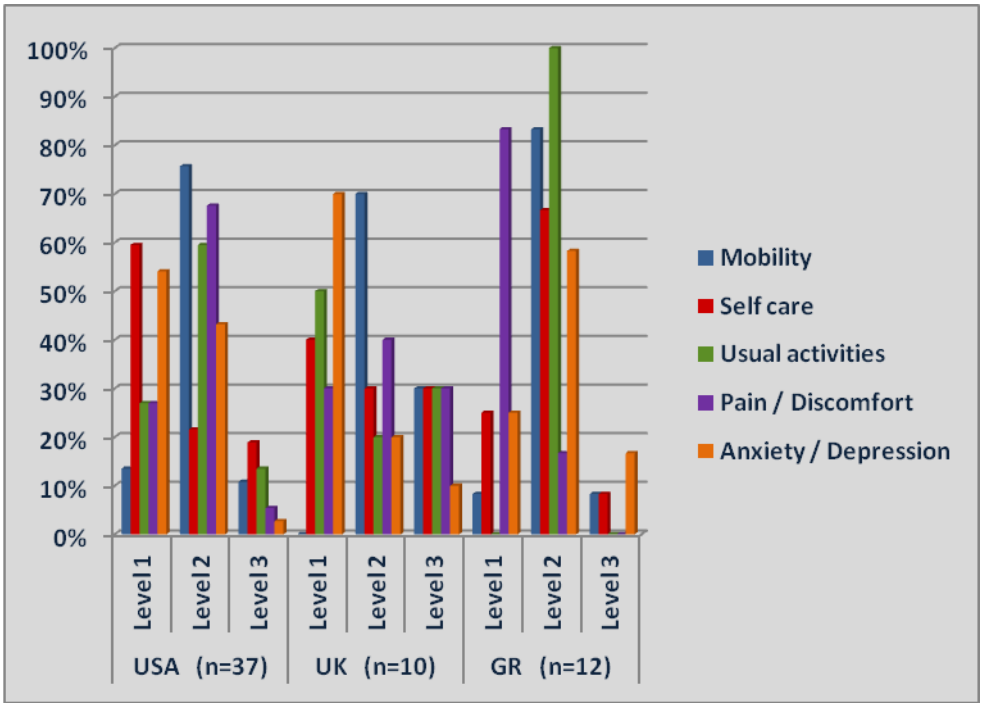

Figure 9.c.2.3: Percentage of people, within each national group, without LBP reporting each health status dimension;
Abbreviation: EQ-5D, Quality of Life

Table 9.c.2.4: .Mean QoL, within each national group, of people with and without the pain presence

Pain category	EQ-5D Index						EQ-VAS					
	Pain in general		Current LBP		MSKP		Pain in general		Current LBP		MSKP	
	Yes	No	Yes	No	Yes	No	Yes	No	Yes	No	Yes	No
USA	0.3±0.3	0.3±0.3	0.3±0.3	0.5±0.3	0.2±0.3	0.4±0.4	67.2±21.6	83.6±9.9	62.7±22.1	78.2±15.4	61.2±20.43	72.0±21.3
mean,	0.5	0.5	0.2	0.6	0.2	0.6	70	80	63.5	80	60	80
SD, mix-max	0.02–0.80	0.02–0.80	-0.2–0.8	-0.1–1.0	-0.2–0.8	-0.6–1.0	5–100	70–95	5–100	40–95	5–97	22–100
	n=106	n=7	n=70	n=37	n=40	n=71	n=106	n=7	n=70	n=37	n=4	n=71
UK mean,	0.3±0.4	n/a	0.3±0.3	0.3±0.4	0.4±0.3	0.3±0.4	59.5±24.0	n/a	56.7±22.9	80.0±16.1	61.8±17.2	58.3±30.1
SD, mix-max	0.5	n=1	0.5	0.2	0.5	0.2	67.5	n=1	65	80	65.5	67.5
	-0.5–0.6		-0.3–0.7	-0.6–0.8	-0.3–0.7	-0.6–0.8	0–98		0–85	50–100	28–85	0–100
	n=42		n=33	n=10	n=20	n=22	n=42		n=33	n=9[2]	n=20	n=22
Greece	0.3±0.4	0.6±0.2	0.3±0.4	0.5±0.3	0.3±0.4	0.5±0.2	51.1±20.2	54.7±11.1	48.9±19.5	55.6±16.9	44.2±21.0	54.1±14.3
mean,	0.5	0.6	0.5	0.6	0.5	0.6	50	50	50	50	40	50
SD, mix-max	-0.6–0.7	-0.1–0.8	-0.6–0.7	0.1–0.9	-0.6–0.7	-0.04-0.9	10–90	38–70	10–80	30–90	10–75	30–80
	n=9	n=33	n=29	n=12	n=17	n=21[1]	n=33	n=8[2]	n=29	n=12	n=17	n=23

[1]Two outliers eliminated, [2]one outlier eliminated;

Abbreviation: EQ-5D, Quality of Life; EQ-VAS, Quality of Life Visual Analogue Scale; LBP, Low Back Pain; MSKP, Musculoskeletal Pain, SD, Standard Deviation

9.c.3. EQ-5D; relation to demographic profile characteristics

Table 9.c.3.1: Percentage of males and females, within each national group, reporting each health status dimension

Subscale	Level	Males (%)			Subscale	Level	Females (%)		
		USA n=76	UK n=22	Greece n=22			USA n=37	UK n=21	Greece n=17
Mobility	1	11.8	0	9.1	**Mobility**	1	2.7	0	5.9
	2	75	90.9	77.3		2	78.4	85.7	76.5
	3	13.2	9.1	13.6		3	18.9	14.3	17.6
Self-care	1	51.3	36.4	31.8	**Self-care**	1	51.4	33.3	52.9
	2	35.5	54.5	54.5		2	40.5	52.4	35.3
	3	13.2	9.1	13.6		3	8.1	14.3	11.8
Usual Activities	1	23.7	22.7	9.1	**Usual Activities**	1	16.2	9.5	17.6
	2	63.2	63.6	77.3		2	54.1	71.4	64.7
	3	13.2	13.6	13.6		3	29.7	19	17.6
Pain/ discomfort	1	13.2	9.1	31.8	**Pain/ discomfort**	1	16.2	4.8	11.8
	2	71.1	59.1	50		2	51.4	66.7	82.4
	3	15.8	31.8	18.2		3	32.4	28.6	5.9
Anxiety/ depression	1	48.7	50	31.8	**Anxiety/ depression**	1	35.1	42.9	11.8
	2	42.1	36.4	54.5		2	54.1	52.4	70.6
	3	9.2	13.6	13.6		3	10.8	4.8	17.6

Table 9.c.3.2: Differences in QoL, within each national group, between people with and without MSKP

EQ-5D	USA Without MSKP n=53 With MSKP n=23	UK Without MSKP n=12 With MSKP n=10	GR Without MSKP n=14 With MSKP n=6
Males	t=0.55, df74 p=0.58, d=0.55 95%CI -0.12, 0.21	t=-1.03, df20 p=0.31, d=0.45 95%CI -0.49, 0.16	U=14.5 p=0.02[1], r=0.51
Females	t=3.18, df33 p=0.003[1], d=1.08 95%CI 0.12, 0.54	t=0.66, df18 p=0.51, d=0.31 95%CI -12.94, 24.94	U=30.0 p=0.55, r=0.14
EQ-VAS			
Males	t=0.84, df84 p=0.4, d=0.21 95%CI -6.36, 15.77	t=3-0.97, df20 p=0.34, d=0.42 95%CI -37.5, 13.67	U=35.5 p=0.58, r=0.12
Females	t=3.81, df105 **p≤0.001*****, d=1.29 95%CI 7.4, 23.6	t=-0.68, df18 p=0.49, d=0.29 95%CI -0.44, 0.22	U=17.5 p=0.07, r=0.43

The presence of MSKP was examined within each gender and it was found that among males those with and without MSKP did not differ significantly in their mean classified or perceived health status. Within females, in the case of the USA the effect sizes were much larger than typical and statistically significant for perceived health status.
[1]not significant post Bonferroni correction; ***Significant at p≤0.001 level, **in bold:** significant following application of the Bonferroni correction;
Abbreviations: EQ-5D, Quality of Life, EQ-VAS, Quality of Life Visual Analogue Scale, MSKP, Musculoskeletal Pain;
Statistical tests: U, Mann-Whitney U test; t, Independent t-test

Table 9.c.3.3: Percentage of people, within each national group, divided in groups by cause of injury, reporting each health status dimension injury

Subscale	Level	USA %		UK %		Greece %	
		Traumatic n=89	Non-traumatic n=24	Traumatic n=34	Non-traumatic n=9	Traumatic n=16	Non-traumatic n=26
Mobility	1	10.1	4.2	0	0	18.8	3.8
	2	75.3	79.2	88.2	88.9	68.8	76.9
	3	14.6	16.7	11.8	11.1	12.5	19.2
Self-care	1	52.8	45.8	38.2	22.2	37.5	42.3
	2	32.6	54.2	50	66.7	50	46.2
	3	14.6	0	11.8	11.1	12.5	11.5
Usual Activities	1	24.7	8.3	14.7	22.2	12.5	15.4
	2	58.4	66.7	67.6	66.7	81.3	65.4
	3	16.9	25	17.6	11.1	6.3	19.2
Pain/ discomfort	1	16.9	4.2	5.9	11.1	37.5	15.4
	2	64	66.7	67.6	44.4	56.3	65.4
	3	19.1	29.2	26.5	44.4	6.3	19.2
Anxiety/ depression	1	50.6	20.8	44.1	46.5	43.8	7.7
	2	40.4	66.7	44.1	44.2	50	69.2
	3	9	12.5	11.8	9.3	6.3	23.1

Abbreviation: EQ-5D, Quality of Life

Table 9.c.3.4: Percentage of people, within each national group, divided in groups by level of injury, reporting each health status dimension

	Level	USA (%)		UK (%)		Greece (%)	
		Tetraplegia n=89	Paraplegia n=24	Tetraplegia n=15	Paraplegia n=27	Tetraplegia n=14	Paraplegia n=28
Mobility	1	9.8	7.7	0	0	7.1	10.7
	2	68.9	84.6	86.7	88.9	71.4	75
	3	21.3	7.7	13.3	11.1	21.4	14.3
Self-care	1	39.3	65.4	20	44.4	21.4	50
	2	39.3	34.6	46.7	55.6	57.1	42.9
	3	21.3	0	33.3	0	21.4	7.1
Usual Activities	1	23	19.2	13.3	18.5	7.1	17.9
	2	57.4	63.5	53.3	74.1	71.4	71.4
	3	19.7	17.3	33.3	7.4	21.4	10.7
Pain/ discomfort	1	18	9.6	20	0	35.7	17.9
	2	70.5	57.7	53.3	70.4	42.9	71.4
	3	11.5	32.7	26.7	29.6	21.4	10.7
Anxiety/ depression	1	55.7	30.8	60	40.7	21.4	21.4
	2	36.1	57.7	33.3	51.9	64.3	60.7
	3	8.2	11.5	6.7	7.4	14.3	17.9

Abbreviation: EQ-5D, Quality of Life

Table 9.c.3.5: Differences in QoL, within each national group, between people with different level of injury

	USA	UK	GR
EQ-5D	t=-0.26, df111 p=0.79 95%CI -0.1, 0.1	U=189.5 p=0.73	U=170.5 p=0.49
EQ-VAS	t=2.48, df111 p≤0.01[1] 95%CI 2.0, 17.6	t=0.98, df39 p=0.32 95%CI -7.3, 21.4	t=-0.16, df40 p=0.86 95%CI -13.6, 11.5

[1]not significant post Bonferroni correction;
Abbreviations: EQ-5D, Quality of Life, EQ-VAS, Quality of Life Visual Analogue Scale;
Statistical tests: U, Mann-Whitney U test; t, Independent t-test

Table 9.c.3.6: Mean QoL for people, within each national group, divided into groups by demographic profile characteristics. Differences in mean QoL between groups within each national group

	USA				UK				Greece			
	EQ-5D Index	Statistical test	EQ-VAS	Statistical test	EQ-5D Index	Statistical test	EQ-VAS	Statistical test	EQ-5D Index	Statistical test	EQ-VAS	Statistical test
Traumatic	0.4±0.3 -0.6-10 n=89	t=1.14 df111 p=0.25 95% CI	72.4±19. 6 80 22 – 100 n=88	t=4.26 df110 **p≤0.001***** 95% CI -	0.3±0.3 0.5 -0.6 – 0.8 n=34	U=151 p=0.95	56.9±25.4 65 0 – 100 n=34	U=100 p=0.11	0.5±0.3 0.6 -0.2 – 0.9 n=16	U=143.5 p=0.09	58.6±17.0 56.5 30 – 90 n=16	t=2.04 df40 p≤0.04[1] 95% CI -
Non-traumatic	0.3±0.3 0.3 -0.2-0.7 n=24	-0.06, 0.25	53.9±17. 5 50 30 – 24 n=24	0.06, 0.25	0.3±0.4 0.5 -0.2 - 0.7 n=9		73.8±12.8 70 60 – 98 n=9		0.3±0.4 0.5 -0.6 - 0.7 n=26		46.8±18.7 49.7 10 – 70 n=26	0.15, 23.3
Tetraplegia	0.4±0.3 0.3 -0.6 – 0.9 n=61	t=-0.26 df111 p=0.79 95% CI -0.1, 0.1	0.3±0.4 -0.6 – 0.8 n=15	t=2.48 df111 p≤0.01[1] 95% CI 2.0, 17.6	0.3±0.4 0.4 -0.6 – 0.7 n=14	U=189.5 p=0.73	72.7±20.3 80 22 - 100 n=61	t=0.98 df39 p=0.32 95% CI -7.3, 21.4	67.8±24. 4 70.5 20 - 100 n=14	U=170.5 p=0.49	50.6±23.6 50 10 - 90 n=14	t=-0.16 df40 p=0.86 95% CI -13.6, 11.5
Paraplegia	0.4±0.3 0.5 -0.2 - 10 n=52		0.4±0.3 0.5 -0.3 - 0.7 n=27		0.4±0.3 0.6 -0.3 - 0.9 n=28		62.9±21.6 62.5 5 - 100 n=52		60.7±21. 7 70 10 - 85 n=27		51.7±16.3 50 25 - 80 n=28	
Males	0.4±0.3 0.5 -0.6-1.0 n=76	U=1120. 5 p=0.08	68.7±22. 2 75 5-99 n=76	t=0.31 df111 p=0.75, 95% CI -7.1, 9.8	0.3±0.4 0.5 -0.6-0.8 n=22	U=213 p=0.66	58.6±28.6 70.5 0-98 n=22	t=-0.50 df51 p=0.61 95% CI -19.0,	0.4±0.4 0.5 -0.6-0.9 n=22	U=176.5 p=0.76	53.4±20.9 52.5 10-90 n=22	t=0.70 df37 p=0.48 95% CI -8.1, 16.8
Females	0.3±0.3 0.2 -0.2-0.8 n=37		67.3±19. 5 70 30-100 n=37		0.3±0.3 0.5 -0.3-0.7 n=21		62.4±19.8 65 20-100 n=21	11.4	0.4±0.4 0.6 -0.3-0.7 n=17		49.0±16.5 79.5 25-70 n=17	

[1]not significant post Bonferroni correction; Abbreviation: EQ-5D, Quality of Life; EQ-VAS, Quality of Life Visual Analogue Scale; SD, Standard Deviation; *Statistical tests*: t, Independent t-test, U, Mann-Whitney U test

Table 9.c.3.7: Correlations between QoL and age for respondents within each national group

	EQ-5D			EQ-VAS		
	USA	**UK**	**GR**	**USA**	**UK**	**GR**
Age	r=0.005 p=0.96 n=107	r=-0.12 p=0.45 n=41	r=0.10 p=0.51 n=42	r=-0.25 p=0.008[1] n=107	r=-0.27 p=0.08 n=41	r=-0.29 p=0.05[1] n=42

[1]not significant post Bonferroni correction;
Abbreviations: EQ-5D, Quality of Life, EQ-VAS, Quality of Life Visual Analogue Scale;
Statistical test: r, Pearson's correlation

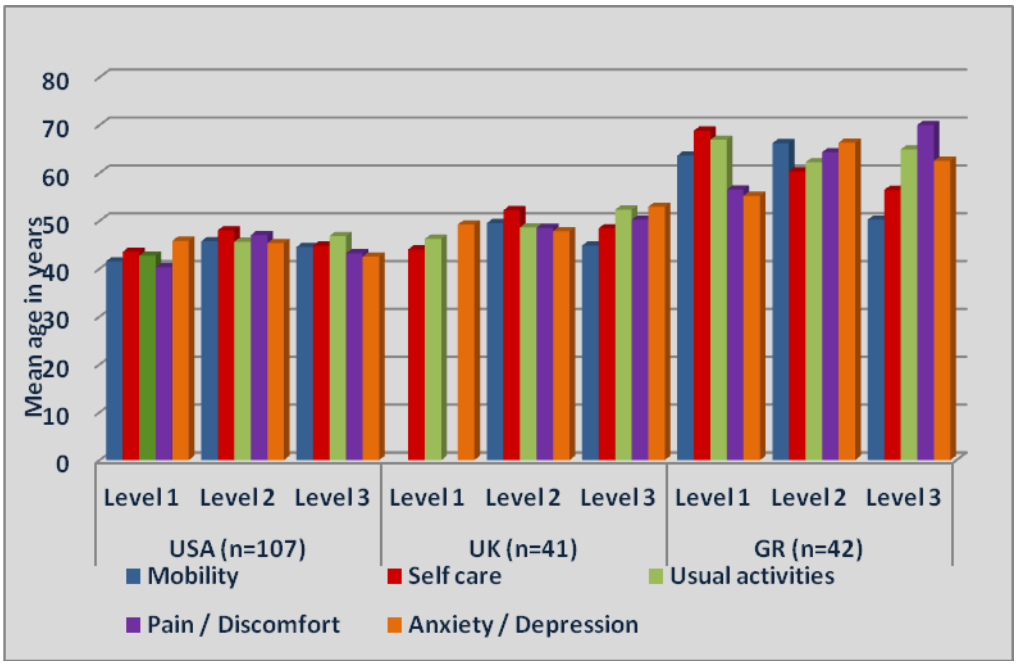

Figure 9.c.3.1: Mean age of respondents, within each national group, for each health status dimension

Table 9.c.3.8: Mean age of respondents, within each national group, in groups divided by each health status dimension

	Level	USA mean, SD mix-max	UK mean, SD mix-max	Greece mean, SD mix-max		Level	USA mean, SD mix-max	UK mean, SD mix-max	Greece mean, SD mix-max
		n=107	n=41	n=42			n=107	n=41	n=42
Mobility	1	41.5±8.1 , 39.4 33.4 – 54.7	n/a as n=0	63.6±7.2, 63.7 56.5 – 70.6	Pain/ discomfort	1	40.3±11.1, 36.9 26.6 – 61.9	n/a as n=1	56.5±15.9, 58.5 37.5 – 79.9
	2	45.7±10.2, 46.2 9.8 – 66.8	49.5±12.9, 52.7 26.1 – 73.2	66.2±14.3, 67.1 37.5 – 91.7		2	47.0±10.3, 49.6 23.0 – 66.8	48.5±13.7, 49.7 26.1 – 73.2	64.3±16.6, 67.4 30.9 – 91.7
	3	44.5±13.8, 43.7 23.0 – 65.3	44.8±11.9, 49.7 27.3 – 57.9	50.2±23.0, 40.2 30.9 – 90		3	43.2±10.3, 43.4 19.8 – 60.3	50.2±11.4, 53.6 27.3 – 66.4	70.0±14.0, 71.0 47.0 – 89.1
Self care	1	43.3±10.3, 42.9 19.8 – 59.8	44.0±12.4, 49.0 26.1 – 60.1	68.8±9.8, 68.1 53.6 – 83.8	Anxiety/ depression	1	45.8±10.7, 46.1 26.3 – 65.3	49.2±12.6, 52.7 29.2 – 72.3	55.2±16.6, 58.5 31.2 – 83.8
	2	48.0±9.8, 49.7 26.6 – 65.3	52.2±11.6, 54.3 27.3 – 73.2	60.3±18.6, 60.2 30.7 – 91.7		2	45.3±10.7, 45.8 23.0 – 66.8	47.8±13.9, 49.4 26.1 – 73.2	66.3±16.1, 68 30.9 – 91.7
	3	44.8±13.2, 43.8 23.4 – 66.8	48.4±16.9, 43.5 29.2 – 72.3	56.4±21.6, 47.0 37.6 – 90		3	42.5±10.8, 42.6 19.8 – 60.3	52.9±9.1, 54.1 41.4 – 62.2	62.5±15.4, 67.1 37.6 – 76.5
Usual Activities	1	42.7±10.6, 41.1 23.0 – 61.9	46.2±12.7, 50.2 26.7 – 60.1	66.9±4.1, 68.0 58.8 – 70.6					
	2	45.6±10.8, 46.3 19.8 – 66.8	48.6±13.4, 53.2 26.1 – 73.2	62.2±17.4, 59.9 30.9 – 91.7					
	3	46.8±10.2, 45.7 23.4 – 65.3	52.3±10.8, 50.3 39.1 – 72.3	64.9±19.4, 70.1 37.6 – 90					

Abbreviation: EQ-5D, Quality of Life; SD, Standard Deviation

Table 9.c.3.9: Correlations between QoL and time since injury for respondents within each national group

	EQ-5D			EQ-VAS		
	USA	**UK**	**GR**	**USA**	**UK**	**GR**
Time since injury	r=0.001 p=0.84 n=112	r=-0.16 p=0.30 n=43	r=-0.07 p=0.65 n=42	r=0.014 p=0.13 n=112	r=-0.003 p=0.98 n=43	r=-0.29 p=0.22 n=42

**Significant at p≤0.01 level;
Abbreviations: EQ-5D, Quality of Life, EQ-VAS, Quality of Life Visual Analogue Scale;
Statistical test: r, Pearson's correlation

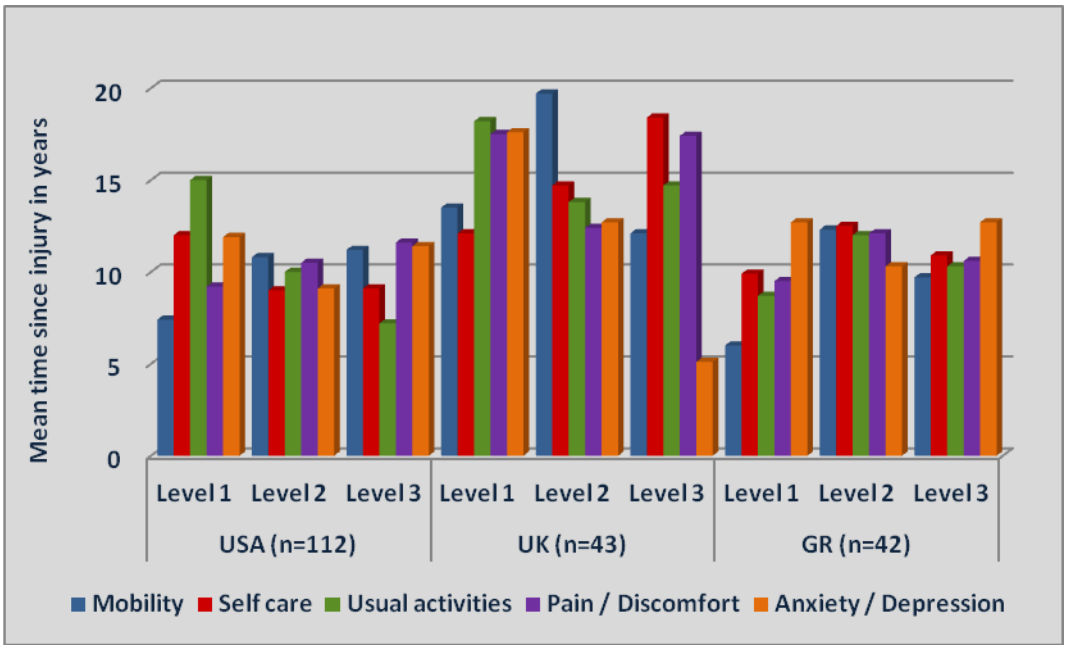

Figure 9.c.3.2: Mean time since injury of the respondents, within each national group, for each health status dimension

Table 9.c.3.10: Mean time since injury of respondents, within each national group, in groups divided by the health status dimensions

	Level	USA mean, SD mix-max	UK mean, SD mix-max	Greece mean, SD mix-max		Level	USA mean, SD mix-max	UK mean, SD mix-max	Greece mean, SD mix-max
		Time since injury n=112	Time since injury n=43	Time since injury n=42			Time since injury n=112	Time since injury n=43	Time since injury n=42
Mobility	1	7.4±5.7 , 6.0 0.6 – 19.4	n/a as n=0	6.0±3.5, 6.6 1.8 – 10.0	**Pain/ discomfort**	1	9.2±11.4, 3.9 0.9 – 41.7	17.5±9.3, 16.2 8.9 – 27.4	9.5±5.6, 9.6 1.5 – 21.1
	2	10.8±10.8, 6.5 0.3 - 44	13.5±12.6, 8.2 0.9 – 43.8	12.3±8.7, 9.5 1.4 – 34.3		2	10.5±11.3, 5.9 0.3 – 44.2	12.4±12.1, 6.6 0.9 – 43.8	12.1±9.1, 8.9 1.4 – 34.3
	3	11.2±13.3, 3.2 0.3 – 44.2	19.7±10.0, 22 8.1 – 30.8	9.7±6.8, 7.6 3.2 – 19.0		3	11.6±9.3, 9.3 0.5 – 31.1	17.4±13.7, 10.7 3.3 – 43.2	10.6±7.7, 8.6 4.8 – 26.0
Self-care	1	12.0±11.3, 6.6 0.4 - 44	12.1±11.8, 8.6 0.9 – 34.9	9.9±8.4, 8.1 1.4 – 31.0	**Anxiety/ depression**	1	11.9±12.1, 6.1 0.4 – 44.0	17.6±13.5, 18.0 1.3 – 43.8	12.7±8.9, 9.8 1.4 – 23.6
	2	9.0±10.9, 3.9 0.3 – 44.2	14.7±13.3, 9.7 0.9 – 43.8	12.5±8.1, 9.7 1.5 – 34.3		2	9.1±9.7, 5.7 0.3 – 44.2	12.7±11.5, 9.7 0.9 – 35.1	10.3±7.3, 8.9 1.5 – 31.0
	3	9.1±8.3, 5.5 1.1 – 27.0	18.4±11.0, 22 5.5 – 29.2	10.9±8.5, 6.4 3.2 – 21.1		3	11.4±10.4, 7.0 0.6 – 30.1	5.1±2.2, 4.6 3.3 – 8.1	12.7±10.7, 9.0 3.2 – 34.3
Usual Activities	1	15.0±11.7, 12.4 2.4 – 41.7	18.2±10.2, 19.7 1.0 – 28.4	8.7±6.5, 8.1 1.6 – 20.7					
	2	10.0±11.3, 4.7 0.3 – 44.2	13.8±13.2, 7.8 0.9 – 43.8	12.0±8.7, 9.6 1.4 – 34.3					
	3	7.2±6.1, 5.0 0.3 – 17.5	14.7±11.6, 8.1 3.5 – 30.8	10.3±7.1, 7.7 3.2 – 19.0					

Abbreviation: EQ-5D, Quality of Life; SD, Standard Deviation

Table 9.c.3.11: Percentage of people, within each national group, divided in groups by marital status, reporting the health status dimensions

	Level	Total group % n=194		USA % n=111		UK % n=42		Greece % n=41	
		Married[1]	Single[2]	Married[1]	Single[2]	Married[1]	Single[2]	Married[1]	Single[2]
Mobility	1	7.9	5.9	8.7	9.5	20	0	14.3	0
	2	80.2	73.5	79.7	69	86.2	92.3	75	69.2
	3	11.9	20.6	11.6	21.4	13.8	7.7	10.7	30.8
Self-care	1	46.8	44.1	53.6	47.6	34.5	38.5	42.9	38.5
	2	42.1	42.6	36.2	38.1	51.7	53.8	46.4	46.2
	3	11.1	13.2	10.1	14.3	13.8	7.7	10.7	15.4
Usual Activities	1	17.5	20.6	17.4	26.2	13.8	23.1	21.4	0
	2	61.9	67.6	60.9	59.5	62.1	76.9	64.3	84.6
	3	20.6	11.8	21.7	14.3	24.1	0	14.3	15.4
Pain/ discomfort	1	15.9	13.2	13	16.7	6.9	7.7	32.1	7.7
	2	59.5	70.6	62.3	69	62.1	61.5	50	84.6
	3	24.6	16.2	24.6	14.3	31	30.8	17.9	7.7
Anxiety/ depression	1	38.1	44.1	43.5	47.6	44.8	46.2	17.9	30.8
	2	50.8	45.6	49.3	40.5	44.8	46.2	60.7	61.5
	3	11.1	10.3	7.2	11.9	10.3		21.4	7.7

[1]Married or in relationship, [2]Single or divorced or widowed.
Abbreviation:QoL, Quality of Life; EQ-5D, Quality of Life

Table 9.c.3.12: Percentage of people, within each national group, divided in groups by the level of education, reporting the health status dimensions

	Level	Total group (%)				USA (%)				UK (%)				Greece (%)			
		Compu-lsory n=22	High School n=44	College / University n=96	Master or PhD n=34	Compu-lsory n=1	High School n=30	College / University n=57	Master or PhD n=25	Compu-lsory n=6	High School n=3	College / University n=21	Master or PhD n=7	Compu-lsory n=14	High School n=10	College / University n=15	Master or PhD n=2
Mobility	1	4.5	9.1	6.3	8.8	100	3.3	8.8	12	85.7	75	87.5	100	0	30	637	0
	2	81.5	77.3	77.1	79.4	0	83.3	71.9	80	0	0	0	0	85.7	60	80	0
	3	13.6	13.6	16.7	11.8	0	13.3	19.3	8	14.3	25	12.5	0	14.3	10	13.3	100
Self care	1	36.4	45.5	45.8	50	100	43.3	50.9	60	14.3	0	45.8	28.6	42.9	70	26.7	0
	2	54.5	36.4	43.8	41.2	0	33.3	38.6	40	85.7	75	45.8	42.9	42.9	30	60	50
	3	9.1	18.2	10.4	8.8	0	23.3	10.5	0	0	25	8.3	28.6	14.3	0	13.3	50
Usual Activities	1	9.1	15.9	21.9	17.6	100	6.7	28.1	20	14.3	0	16.7	14.3	0	50	6.7	0
	2	77.3	59.1	63.5	64.7	0	66.7	56.1	64	85.7	50	66.7	71.4	78.6	40	86.7	50
	3	13.6	25	14.6	17.6	0	26.7	15.8	15.8	0	50	16.7	14.3	21.4	10	6.7	50
Pain/ discomfort	1	18.2	9.1	17.7	11.8	100	6.7	15.8	16	14.3	25	4.2	0	14.3	10	46.7	0
	2	59.1	59.1	64.6	70.6	0	60	66.7	68	57.1	25	66.7	85.7	64.3	70	53.3	50
	3	22.7	31.8	17.7	17.6	0	33.3	17.5	16	28.6	50	29.2	14.3	21.4	20	0	50
Anxiety/ depression	1	27.3	38.6	40.6	47.1	100	43.3	43.9	44	42.9	50	37.3	71.4	14.3	20	33.3	0
	2	54.5	50	49	47.1	0	43.3	45.6	52	42.9	50	50	28.6	64.3	70	60	50
	3	18.2	11.4	10.4	5.9	0	13.3	10.5	4	14.3	0	12.5	0	21.4	10	6.7	50

Abbreviation: QoL, Quality of Life; EQ-5D, Quality of Life

Table 9.c.3.13: Percentage of people, within each national group, divided in groups by employment status, reporting the health status dimensions

	Level	Total group (%)			USA (%)			UK (%)			Greece (%)		
		Employ-ed n=105	**Unemploy-ed** n=61	**Retired** n=31	**Employed** n=70	**Unemplo-yed** n=39	**Retired** n=3	**Employed** n=70	**Unemplo-yed** n=39	**Retired** n=3	**Employed** n=70	**Unemplo-yed** n=39	**Retired** n=3
Mobility	1	9.5	6.6	0	11.4	5.1	0	0	0	0	11.8	33.3	0
	2	77.2	72.1	93.5	74.3	76.9	100	100	68.6	100	64.7	50	89.5
	3	13.3	21.3	6.5	14.3	17.9	0	0	31.3	0	23.5	16.7	10.5
Self-care	1	50.3	41	38.7	55.7	43.6	66.7	44.4	31.3	22.2	35.3	50	42.1
	2	40	41	54.8	34.3	41	33.3	50	50	66.7	52.9	16.7	52.6
	3	9.5	18	6.5	10	15.4	0	5.6	18.8	11.1	11.8	33.3	5.3
Usual Activities	1	22.9	13.1	16.1	28.6	10.3	0	16.7	12.5	22.2	5.9	33.3	15.8
	2	68.6	54.1	71	62.9	53.8	100	72.2	62.5	66.7	88.2	33.3	68.4
	3	8.6	32.8	12.9	8.6	35.9	0	11.1	25	11.1	5.9	33.3	15.8
Pain/ discomfort	1	20	3.3	19.4	18.6	51	33.3	11.1	0	11.1	35.3	0	21.1
	2	67.6	62.3	51.6	67.1	61.5	33.3	72.2	62.5	44.4	64.7	66.7	57.9
	3	12.4	34.4	29	14.3	33.3	33.3	16.7	37.5	44.4	0	33.3	21.1
Anxiety/ depression	1	44.8	36.1	29	47.1	33.3	100	44.4	50	44.4	35.3	16.7	10.5
	2	48.6	47.5	54.8	44.3	53.8	0	55.6	31.3	44.4	58.8	50	68.4
	3	6.7	16.4	16.1	8.6	12.8	0	0	18.8	11.1	5.9	33.3	21.1

Abbreviation: QoL, Quality of Life; EQ-5D, Quality of Life

Table 9.c.3.14: Differences in QoL between people, within each national group, with different marital status

	USA n=111	UK n=42	GR n=41
EQ-5D	t=0.17, df109 p=0.86, 95%CI -0.12, 0.14	U=159.5 p=0.42	U=126.5 p=0.11
EQ-VAS	t=0.79, df109 p=0.42 95%CI -11.5, 0.49	U=143 p=0.21	U=153.5 p=0.42

Abbreviations: EQ-5D, Quality of Life, EQ-VAS, Quality of Life Visual Analogue Scale;
Statistical tests: U, Mann-Whitney U test; t, Independent t-test

Table 9.c.3.15: Differences in QoL between people, within each national group, with different education level

	USA n=111[1]	UK n=42	GR n=41
EQ-5D	H=5.16 p=0.07	H=3.12 p=0.37	H=6.54 p=0.08
EQ-VAS	H=2.06 p=0.55	H=3.05 p=0.38	H=11.5 p=0.009[2]

[1]"Compulsory/no education" category was excluded because it only included 1 respondent thus biasing analysis; [2]not significant post Bonferroni correction;
Abbreviations: EQ-5D, Quality of Life, EQ-VAS, Quality of Life Visual Analogue Scale;
Statistical test: H, Kruskal-Wallis H test

9.c.4. EQ-5D; relation to pain/LBP days, free weeks, onset

Table 9.c.4.1: Percentage of people,within each national group, divided in groups by the number of LBP days felt per month, reporting the health status dimensions

		USA (%)				UK (%)				GR (%)			
	Level	**1-9 days**	**10-20 days**	**21-30 days**	**Everyday**	**1-9 days**	**10-20 days**	**21-30 days**	**Everyday**	**1-9 days**	**10-20 days**	**21-30 days**	**Everyday**
Mobility	1	5.3	7.1	0	11.4	0	0	0	0	9.1	20	0	0
	2	78.9	78.6	88.9	74.3	100	100	75	94.7	81.8	70	60	75
	3	15.8	14.3	11.1	14.3	0	0	25	5.3	9.1	10	40	25
Self-care	1	57.9	57.1	44.4	45.7	33.5	100	50	21.1	63.6	40	40	50
	2	26.3	35.7	55.6	48.6	50	0	50	73.7	27.3	60	40	25
	3	15.8	7.1	6	5.7	16.7	0	0	5.3	9.2	0	20	25
Usual activities	1	26.3	28.6	22.2	11.4	16.7	33.3	25	0	27.3	20	20	0
	2	68.4	64.3	44.4	60	66.7	66.7	75	84.2	63.6	70	60	50
	3	5.3	7.1	33.3	28.6	16.7	0	0	15.8	9.1	10	20	50
Pain / Discomfort	1	21.1	21.4	0	0	0	0	0	0	0	0	0	0
	2	68.4	64.3	55.6	65.7	100	66.7	50	68.4	81.8	90	80	50
	3	10.5	14.3	44.4	34.3	0	33.3	50	31.6	18.2	10	20	50
Anxiety / Depression	1	57.9	35.7	33.3	34.3	83.8	100	0	31.6	9.1	10	40	50
	2	36.8	57.1	55.6	45.7	0	0	100	57.9	81.8	80	40	25
	3	5.3	7.1	11.1	20	16.7	0	0	10.5	9.1	10	20	25

Abbreviation: QoL, Quality of Life; EQ-5D, Quality of Life; LBP, Low Back Pain

Table 9.c.4.2: Mean EQ-5D index for people, within each national group, divided in groups by the number of pain or LBP days felt monthly

Number of pain days	**USA** mean, SD, mix-max	**UK** mean, SD, mix-max	**Greece** mean, SD, mix-max	**Frequency of pain free weeks**	**USA** mean, SD, mix-max	**UK** mean, SD, mix-max	**Greece** mean, SD, mix-max
1-9	0.6±0.3 , 0.7 -0.1 – 1.0, n=12	0.7±0.1 , 0.7 -0.6 – 0.8, n=4	0.4±0.4, 0.6 -0.3 – 0.7, n=12	Most time	0.5±0.3, 0.7 0.2 – 0.8, n=7	0.7±0.1, 0.7 0.6 – 0.8, n=3	0.4±0.4, 0.5 -0.3 – 0.7, n=5
10-20	0.5±0.3 , 0.6 -0.1 – 0.7, n=15	0.3±0.5, 0.3 -0.1 – 0.7, n=15	0.3±0.4, 0.5 -0.2 – 0.7, n=9	Frequently	0.5±0.2, 0.6 0.1– 0.7, n=8	0.4±0.4, 0.4 0.1 – 0.7, n=2	0.5±0.3, 0.6 0.002–0.7, n=2
21-30	0.2±0.4 , 0.2 -0.6 – 0.7, n=10	0.3±0.4, 0.4 -0.3 – 0.6, n=4	0.4±0.3, 0.5 -0.1 – 0.6, n=4	Sometimes	0.3±0.3, 0.5 -0.1 – 0.7, n=7	0.4±0.3, 0.6 -0.1 – 0.7, n=4	0.5±0.3, 0.6 -0.2 – 0.7, n=7
Everyday	0.3±0.3 , 0.2 -0.2 – 0.8, n=67	0.3±0.3, 0.5 -0.6 – 0.7, n=32	0.2±0.5, 0.3 -0.6 – 0.7, n=6	Not often	0.6±0.1, 0.6 0.6 – 0.7, n=3	0.3±0.3, 0.2 -0.1 – 0.7, n=3	0.2±0.4, -0.02 -0.2 – 0.7, n=7
Number of LBP days				Rarely	0.4±0.5, 0.6 -0.6 – 1.0, n=13	0.6±0.1, 0.6 0.5 – 0.6, n=4	n/a as n=0
1-9	0.5±0.4 , 0.6 -0.6 – 1.0, n=19	0.5±0.3 , 0.6 0.1 – 0.6, n=6	0.4±0.4 , 0.6 -0.2 – 0.7, n=11	Always have pain	0.3±0.3, 0.2 -0.2 – 0.8, n=57	0.2±0.4, 0.1 -0.6 – 0.7, n=24	-0.1±0.4, -0.1 -0.6 – 0.3, n=1
10-20	0.4±0.3 , 0.6 -0.1 – 0.8, n=14	0.5±0.3 , 0.7 0.2 – 0.5, n=3	0.4±0.3 , 0.5 -0.2 – 0.7, n=10	Frequency of LBP free weeks			
21-30	0.2±0.3 , 0.2 -0.1 – 0.7, n=9	0.2±0.4 , 0.3 -0.3 – 0.7, n=4	0.2±0.4 , 0.1 -0.2 – 0.7, n=5	Most time	0.5±0.2, 0.6 0.1 – 0.7, n=7	0.3±0.3, 0.3 0.1 – 0.6, n=2	0.5±0.3, 0.6 -0.2 – 0.7, n=6
Everyday	0.2±0.3 , 0.2 -0.2 – 0.8, n=35	0.3±0.3 , 0.5 -0.2 – 0.7, n=19	0.2±0.6 , 0.3 -0.6 – 0.7, n=4	Frequently	n/a as n=0	0.4±0.3, 0.4 0.2 – 0.7, n=2	0.5±0.2, 0.6 0.002–0.7, n=7
				Sometimes	0.3±0.4, 0.1 -0.1 – 0.7, n=3	0.4±0.4, 0.4 0.1 – 0.7, n=2	0.4±0.4, 0.6 -0.2 – 0.7, n=7
				Not often	0.4±0.4, 0.6 -0. – 1.0, n=15	0.7±0.1, 0.7 0.6 – 0.7, n=2	n/a as n=1
				Rarely	0.2±0.3, 0.2 -0.2 – 0.8, n=30	0.5±0.3, 0.6 -0.1 – 0.1, n=6	0.3±0.4, 0.3 -0.2 – 0.6, n=6
				Always have pain	0.4±0.4, 0.6 -0.3 – 0.7, n=12	0.2±0.3, 0.1 -0.3 – 0.6, n=13	-0.3±0.3, -0.3 -0.6 – -0.1, n=2

Abbreviation: LBP, Low Back Pain; SD, Standard Deviation

Table 9.c.4.3: Percentage of people, within each national group, divided in groups by the frequency of LBP free weeks, reporting each health status dimension

	Level	USA %						UK %						Greece %					
		Most time n=7	Frequently n=5	Sometimes n=3	Not often n=15	Rarely n=30	Always have pain n=57	Most time n=2	Frequently n=2	Sometimes n=2	Not often n=2	Rarely n=6	Always have pain n=13	Most time n=6	Frequ-ntly n=7	Someti-mes n=7	Not often n=6	Rarely n=1	Always have pain n=2
Mobility	1	0	20	0	6.7	13.3	71.4	0	0	0	0	0	0	33.3	14.3	0	0	0	0
	2	85.7	60	100	80	76.7	28.6	100	100	100	100	100	84.6	66.7	71.4	71.4	100	100	50
	3	14.3	20	0	3.3	10	0	0	0	0	0	0	75.4	0	14.3	28.6	0	0	50
Self care	1	71.4	0	40	33.3	66.7	43.3	50	100	50	50	50	7.7	50	57.1	42.9	66.7	100	0
	2	28.6	0	40	66.6	26.7	50	50	0	0	50	50	84.6	33.3	42.9	42.9	33.3	0	50
	3	0	0	20	0	6.7	6.7	0	0	50	0	0	7.7	16.7	0	14.3	0	0	50
Usual Activities	1	28.6	0	60	0	20	10	0	50	0	50	16.7	0	50	14.3	0	0	0	0
	2	71.4	0	0	33.3	60	63.3	100	50	50	50	83.3	76.9	33.3	85.7	71.4	100	0	0
	3	0	0	40	66.7	20	26.7	0	0	50	0	0	23.1	16.7	0	28.6	0	100	100
Pain/ discomfort	1	14.3	0	20	0	13.3	0	0	0	0	0	0	0	0	0	0	0	0	0
	2	71.4	0	60	66.7	66.7	56.7	50	50	100	100	83.3	61.5	83.3	100	100	50	100	0
	3	14.3	0	20	33.3	20	43.3	50	50	0	0	16.7	38.5	16.7	0	0	50	0	100
Anxiety/ depression	1	42.9	0	20	66.7	46.7	33.3	50	100	100	100	33.3	23.1	0	28.6	28.6	0	100	0
	2	57.1	0	60	33.6	33.3	50	50	0	0	0	66.7	61.5	100	71.4	57.1	66.7	0	50
	3	0	0	20	0	20	16.7	0	0	0	0	0	15.4	0	0	14.3	33.3	0	50

Abbreviation: EQ-5D, Quality of Life; LBP, Low Back Pain

Table 9.c.4.4: Percentage of people, within each national group, divided in groups by the frequency of pain free weeks, reporting each health status dimension

	Level	USA (%)						UK (%)					Greece (%)					
		Most time n=7	Freque-ntly n=8	Some-times n=7	Not often n=3	Rarely n=13	Always have pain n=57	Most time n=3	Freque-ntly n=2	Some-times n=4	Not often n=3	Rarely n=4	Always have pain n=24	Most time n=5	Freque-ntly n=7	Some times n=7	Not often n=7	Rarel y n=1	Always have pain n=4
Mobility	1	0	12.5	0	0	7.7	10.5	0	0	0	0	0	0	40	14.3	0	0	0	0
	2	85.7	75	71.4	100	69.2	78.9	100	50	75	100	100	87.5	40	71.4	85.7	85.7	100	75
	3	14.3	12.5	28.6	0	23.1	10.5	0	50	25	0	0	12.5	20	14.3	14.3	14.3	0	25
Self care	1	57.1	50	14.3	100	69.2	47.4	33.3	100	50	66.7	50	25	40	57.1	42.9	57.1	100	0
	2	28.6	50	57.1	0	7.7	43.9	66.7	0	25	33.3	50	62.5	40	42.9	57.1	28.6	0	25
	3	14.3	0	28.6	0	23.1	8.8	0	0	25	0	0	12.5	20	0	0	14.3	0	75
Usual Activities	1	28.6	25	14.3	0	38.5	14	66.7	50	0	66.7	25	4.2	40	28.6	0	28.6	0	0
	2	71.4	75	71.3	100	38.5	63.2	33.3	50	75	33.3	75	75	40	71.4	85.7	57.1	100	25
	3	0	0	14.3	0	23.1	22.8	0	0	25	0	0	20.8	20	0	14.3	14.3	0	75
Pain/ discomfort	1	42.9	25	14.3	0	7.7	0	66.7	0	0	0	0	0	0	0	0	0	0	25
	2	57.1	75	85.7	100	76.9	64.9	33.7	100	100	33.3	100	58.3	100	100	100	57.1	100	0
	3	0	0	0	0	15.4	35.1	0	0	0	66.7	0	41.7	0	0	0	42.9	0	75
Anxiety/ depression	1	57.1	37.5	42.9	33.3	46.2	40.4	100	50	50	66.7	0	41.7	0	14.3	28.6	14.3	0	25
	2	42.9	50	57.1	66.7	38.5	47.4	0	50	50	33.3	100	41.7	80	71.4	57.1	57.1	100	50
	3	0	12.5	0	0	15.4	12.3	0	0	0	0	0	16.7	20	14.3	14.3	28.6	0	25

Table 9.c.4.5: Percentage of people, within each national group, divided in groups by the time of pain onset post iSCI, reporting each health status dimension

	Level	USA (%)					UK (%)					Greece (%)				
		Immedi-ately n=48	Within 1 month n=20	1-6 months n=16	6 months –1 year n=3	After1 year n=12	Immedi-ately after n=18	Within 1 month n=7	1-6 months n=6	6 months –1 year n=4	After 1 year n=5	Imme-diately after n=9	Within 1 month n=5	1-6 months n=12	6 months –1 year n=3	After1 year n=3
Mobility	1	10.4	5	6.3	0	0	0	0	0	0	0	0	20	8.3	0	33.3
	2	79.2	75	87.5	66.7	66.7	94.4	100	83.3	50	80	77.8	60	83.3	100	33.3
	3	10.4	20	6.3	33.3	33.3	5.6	0	16.7	50	20	22.2	20	8.3	0	33.3
Self care	1	54.2	55	37.5	0	50	22.2	57.1	50	25	40	44.4	20	50	66.7	66.7
	2	41.7	30	43.8	100	25	66.7	42.9	50	50	40	44.4	40	33.3	33.3	33.3
	3	4.2	15	18.8	0	25	11.1	0	0	25	20	11.1	40	16.7	0	0
Usual Activities	1	14.6	25	12.5	0	25	5.6	14.3	16.7	25	40	22.2	20	8.3	33.3	33.3
	2	62.5	70	62.5	33.3	66.7	77.8	85.7	66.7	50	40	55.6	40	83.3	66.7	33.3
	3	22.9	5	25	66.7	8.3	16.7	0	16.7	25	20	22.2	20	8.3	0	33.3
Pain/ discomfort	1	10.4	0	0	0	16.7	0	0	0	0	20	0	0	8.3	0	0
	2	58.3	90	68.8	100	75	77.8	57.1	66.7	25	60	66.7	80	75	100	100
	3	31.3	10	31.3	0	8.3	22.2	42.9	33.3	75	20	33.3	20	16.7	0	0
Anxiety/ depression	1	39.6	35	50	66.7	33.3	50	14.3	50	0	100	22.2	20	16.7	0	33.3
	2	43.8	60	43.8	33.3	58.3	38.9	85.7	50	50	0	55.6	80	58.3	100	33.3
	3	16.7	50	6.3	0	8.3	11.1	0	0	50	0	22.2	0	25	0	33.3

Abbreviation: EQ-5D, Quality of Life

Table 9.c.4.6: Percentage of people, within each national group, divided into groups by the time of LBP onset post iSCI, reporting each health status dimension

	Level	USA (%)					UK (%)					Greece (%)				
		Imme-diately after n=25	Within 1 month n=9	1-6 months n=14	6 months – 1 year n=7	After 1 year n=16	Immediate-ly after n=12	Within 1 month n=5	1-6 months n=3	6 months – 1 year n=1	After 1 year n=10	Immedia-tely after n=8	Within 1 month n=5	1-6 months n=9	6 months – 1 year n=5	After 1 year n=2
Mobility	1	12	22.2	0	0	0	0	0	30	0	0	0	20	11.1	0	50
	2	80	66.7	85.7	85.7	75	91.7	100	66.7	100	100	75	60	77.8	100	50
	3	8	11.1	14.3	14.3	25	8.3	0	33.3	0	0	25	20	11.1	0	0
Self care	1	52	44.4	42.9	42.9	56.3	33.3	40	0	0	50	37.5	40	55.6	60	100
	2	48	44.4	50	42.9	25	58.3	60	100	100	50	50	40	44.6	20	0
	3	0	11.1	7.1	14.3	18.8	8.3	0	0	0	0	12.5	20	6	20	0
Usual Activities	1	12	22.2	14.3	14.3	25	16.7	0	0	0	10	25	20	11.4	20	50
	2	56	66.7	64.3	71.4	62.5	75	80	66.7	100	90	50	60	77.8	60	50
	3	32	11.1	21.4	14.3	12.5	8.3	20	33.3	0	0	25	20	11.1	20	0
Pain/ discomfort	1	4	11.1	21.4	0	12.5	0	0	0	0	0	0	0	0	0	0
	2	52	55.6	64.3	57.1	75	66.7	60	33.3	100	80	82.5	100	77.8	80	100
	3	44	33.3	14.3	42.9	12.5	33.3	40	66.7	0	20	37.5	0	22.2	20	0
Anxiety/ depression	1	32	22.2	50	57.1	43.8	50	0	0	100	50	12.5	40	11.1	0	50
	2	52	55.6	42.9	28.6	50	41.7	80	100	0	40	62.5	60	66.7	100	50
	3	16	22.2	7.1	14.3	6.3	8.3	20	0	0	10	25	0	22.7	0	0

Abbreviation: EQ-5D, Quality of Life; LBP, Low Back Pain

Table 9.c.4.7: Mean EQ-5D index reported by people, within each national group, divided in groups by the time of pain or LBP onset post iSCI

Pain onset	USA mean, SD mix-max	UK mean, SD mix-max	Greece mean, SD mix-max
Immediately after iSCI	0.3±0.3 , 0.2 -0.2 – 1.0, n=48	0.4±0.3 , 0.5 -0.2 – 0.7, n=18	0.3±0.4, 0.5 -0.6 – 0.7, n=9
Within 1 month post iSCI	0.4±0.3 , 0.6 -0.1 – 0.7, n=20	0.4±0.2, 0.5 0.1 – 0.6, n=7	0.3±0.4, 0.5 -0.2 – 0.7, n=5
1-6 months post iSCI	0.3±0.3 , 0.3 -0.2 – 0.7, n=16	0.4±0.4, 0.6 -0.3 – 0.7, n=6	0.3±0.4, 0.6 -0.3 – 0.7, n=12
6 months -1years post iSCI	0.3±0.3 , 0.2 0.01 – 0.6, n=3	0.2±0.3,- 0.1 -0.6 – 0.1, n=4	0.6±0.1, 0.6 0.5 – 0.6, n=3
After 1 year post iSCI	0.4±0.4 , 0.6 -0.6 – 0.7, n=12	0.4±0.4 , 0.7 -0.1 – 0.7, n=5	0.4±0.5 , 0.7 -0.2 – 0.7, n=3
LBP onset			
Immediately after iSCI	0.3±0.4 , 0.2 -0.2 – 1.0, n=25	0.3±0.3 , 0.3 -0.1 – 0.7, n=12	0.2±0.5 , 0.3 -0.6 – 0.7, n=8
Within 1 month post iSCI	0.3±0.4 , 0.5 -0.2 – 0.8, n=9	0.3±0.4 , 0.5 -0.2 – 0.6, n=5	0.5±0.4 , 0.6 -0.2 – 0.7, n=5
1-6 months post iSCI	0.4±0.3 , 0.5 -0.1 – 0.8, n=14	0.1±0.4 , - 0.1 -0.3 – 0.5, n=3	0.4±0.4 , 0.6 -0.2 – 0.7, n=9
6 months -1years post iSCI	0.3±0.4 , 0.2 -0.2 – 0.7, n=7	n/a as n=1	0.4±0.4 , 0.6 -0.2 – 0.7, n=5
After 1 year post iSCI	0.5±0.3 , 0.6 0.1 – 0.7, n=15[1]	0.5±0.3 , 0.6 -0.2 – 0.7, n=9[1]	0.7±0.1 , 0.7 0.7 – 0.7, n=2

[1]One outlier eliminated;
Abbreviation: EQ-5D, Quality of Life; LBP, Low Back Pain; SD, Standard Deviation

9.c.5 EQ-5D; relation to pain extent

Table 9.c.5.1: Mean EQ-5D index reported by people, within each national group, divided in groups by the number of areas with pain

Number of areas with pain	USA mean, SD mix-max	UK mean, SD mix-max	Greece mean, SD mix-max
1	0.5±0.3 n=16	n/a as n=1	0.4±0.3 n=4
2	0.4±0.3 n=28	0.3±0.4 n=11	0.1±0.4 n=5
3	0.4±0.4 n=17	0.2±0.3 n=8	0.4±0.3 n=13
4	0.2±0.3 n=16	0.5±0.2 n=8	0.5±0.3 n=6
5	0.2±0.4 n=13	0.3±0.3 n=8	0.5±0.0 n=2
6	0.1±0.3 n=5	0.2±0.4 n=3	n/a as n=1
7	0.1±0.3 n=2	0.2±0.7 n=2	n/a as n=0
8	0.2±0.02 n=2	0.2±0.02 n=2	n/a as n=0
9	0.2±0.01 n=2	n/a as n=1	n/a as n=0

[1]One outlier eliminated;
Abbreviation: EQ-5D, Quality of Life; SD, Standard Deviation

9.d. Pain and function within and across nations

9.d.1. Bonferroni correction

Table 9.d.1.1: Main variables used in analysis of function for cross-national and alpha value set following Bonferroni correction

Main Variables	Tests with following variables		Alpha value following Bonferroni correction
Self-care	1) Pain	13) Country	0.05/25=0.002
Respiration &	2) MSKP	14) Pain days	p≤0.002
Sphincter	3) LBP (current)	15) LBP days	
management	4) Gender	16) Pain free weeks	
Mobility in room	5) Cause of injury	17) LBP free weeks	
& toilet	6) Age	18) Pain onset	
Mobility indoor &	7) Type of injury	19) LBP onset	
outdoor	8) With time since injury	20) Areas with pain	
Total SCIM	9) Intensity of current LBP	21) S-PRI of LBP	
	10) LBP intensity 1 month	22) A-PRI of LBP	
	11) LBP intensity 3 months	23) T-PRI of LBP	
	12) Evaluative PPI of LBP	24) EQ-5D index	
		25) EQ-VAS	

Abbreviations: EQ-5D index, Quality of Life index; EQ-VAS, Quality of Life Visual Analogue Scale; MSKP, Musculoskeletal Pain; LBP, Low Back Pain; PRI, Present Rating Index

9.d.2 SCIM III; general results

Table 9.d.2.1: Descriptive of subscales for SCIM III for USA and UK

Task	UK				USA			
	Mean	SD	Median	Min - Max	Mean	SD	Median	Min - Max
Feeding	2.6	0.6	3	0 -3	2.6	0.6	3	0 – 3
Bathing upper body	1.8	0.9	2	0 – 3	2.2	0.9	2	0 – 3
Bathing lower body	1.6	0.9	2	0 – 3	2.2	0.9	2	0 – 3
Dressing upper body	2.6	1.5	3	0 – 4	3.2	1.3	4	0 – 4
Dressing lower body	2.5	1.6	3	0 – 4	3.0	1.4	4	0 – 4
Grooming	2.5	1.0	3	0 – 3	2.6	0.8	3	0 – 3
Total self-care[1]	13.4	5.7	15	0 – 20	15.7	5.5	18	0 – 20
Respiration	9.8	0.9	10	4 – 10	9.9	1.3	10	0 – 19
Sphincter management - bladder	8.7	5.1	9	0 – 15	10.4	4.7	11	0 – 15
Sphincter management – bowel	6.0	3.1	6.5	0 – 10	6.0	3.5	8	0 – 10
Use toilet	3.3	1.7	4	0 – 5	3.6	1.8	4	0 – 6
Total respiration & sphincter management[2]	27.4	7.7	29	11 – 40	29.8	7.4	30	0 – 40
Mobility in bed	4.6	2.1	6	0 – 6	5.0	1.9	6	0 – 6
Transfer bed – wheelchair	1.6	0.7	2	0 – 2	1.6	0.7	2	0 – 2
Transfer wheelchair – toilet – tub	1.4	0.7	2	0 – 2	1.5	0.8	2	0 – 3
Total mobility room & toilet[3]	7.6	3.4	9	0.10	8.1	3.1	10	0-10
Mobility indoors	3.7	2.3	2.5	1 – 8	3.9	2.6	2	0 – 8
Mobility moderate distance	3.6	3.4	2	0 - 8	3.6	2.5	2	0 – 8
Mobility outdoors	2.6	2.1	2	0 – 8	3.0	2.4	2	0 – 8
Stair management	1.1	1.0	1	0 – 3	1.3	1.2	2	0 – 3
Transfers wheelchair - car	1.3	0.8	2	0 – 2	1.5	0.7	2	0 – 2
Transfers ground – wheelchair	0.5	0.5	1	0 – 1	0.7	0.7	1	0 – 6
Total mobility indoors & outdoors[4]	12.8	8.2	11	0-30	13.8	8.6	11.5	0-30
Total sum[5]	**61.1**	**20.4**	**65.5**	**18 - 100**	**67.4**	**20.5**	**70**	**3 - 100**

[1]Score can range from 0-20, [2]Score can range from 0-40, [3]Score can range from 0-40, [4]Score can range from 0-30 [5]Score can range from 0-40, [4]Score can range from 0-100;
Abbreviation: SCIM, Spinal Cord Independence Measure; SD, Standard Deviation

9.d.3. SCIM III; relation to demographic profile characteristics

Table 9.d.3.1: Mean function scores for males and females, within each national group

	USA Males mean±SD median min-max	**USA Females** mean±SD median min-max	**UK Males** mean±SD median min-max	**UK Females** mean±SD median min-max
Self-care (range 0-20)	15.2±6.0, 18, 0-20, n=81	16.7±4.3, 18, 3-20, n=41	13.8±5.7, 15.5, 1-20, n=30	12.8±5.8, 15, 0-19, n=22
Respiration & sphincter management (range 0-40)	30.4±7.4, 31, 0-40, n=81	28.6±7.2, 28, 15-40, n=41	27.7±7.7, 28.5, 11-40, n=81	27.0±7.8, 29, 12-37, n=22
Mobility room and toilet (range 0-10)	7.7±3.4, 10, 0-10, n=81	9.5±1.0, 10, 6-10, n=37[3]	8.8±1.6, 10, 4-10, n=26[3]	7.4±3.6, 9.5, 0-10, n=22
Mobility indoor & outdoor (range 0-30)	13.6±8.9, 10, 0-30, n=81	14.3±8.3, 16, 3-30, n=41	14.6±8.8, 11.5, 3-30, n=30	10.3±6.7, 9, 0-26, n=22
Total SCIM (range 0-100)	67.8±21.1, 70, 21-100, n=80[2]	71.5±12.971, 40-100, n=38[1]	63.8±20.7, 67.5, 18-100, n=30	57.4±19.8, 63.5, 18-91, n=22

[1]One outlier eliminated [2]Three outliers eliminated, [3]Four outliers eliminated;
Abbreviation: SCIM, Spinal Cord Independence Measure; SD, Standard Deviation

Table 9.d.3.2: Differences in function between males and females within each national group

	Self-care (range 0-20)	**Respiration & sphincter management** (range 0-40)	**Mobility room and toilet** (range 0-10)	**Mobility indoor & outdoor** (range0-30)	**Total SCIM** (range 0-100)
USA	t=-1.37, df120 p=0.17 95% CI -3.5, 0.6 U=1537.5 p=0.49	t=1.38, df120 p=0.17 95% CI -0.8, 4.7	U=247 p=0.41	t=-0.39, df129 p=0.69 95% CI -3.9, 2.6	U=1449.5 p=0.68
UK	U=283.5 p=0.38	t=0.30, df50 p=0.76 95% CI -3.7, 5.0	U=153 p=0.15	t=1.92, df50 p=0.06 95% CI -0.1, 8.8	t=1.1, df50 p=0.27 95% CI -5.1, 17.8
Greece	Refer to Appendix 8: Table 8.3.1				

Abbreviation: SCIM, Spinal Cord Independence Measure;
Statistical tests: U, Mann-Whitney U test; t, Independent t-test

Table 9.d.3.2: Differences in function between males and females within each national group

	Self-care (range 0-20)	**Respiration & sphincter management** (range 0-40)	**Mobility room and toilet** (range 0-10)	**Mobility indoor & outdoor** (range0-30)	**Total SCIM** (range 0-100)
USA	t=-1.37, df120 p=0.17 95% CI -3.5, 0.6 U=1537.5 p=0.49	t=1.38, df120 p=0.17 95% CI -0.8, 4.7	U=247 p=0.41	t=-0.39, df129 p=0.69 95% CI -3.9, 2.6	U=1449.5 p=0.68
UK	U=283.5 p=0.38	t=0.30, df50 p=0.76 95% CI -3.7, 5.0	U=153 p=0.15	t=1.92, df50 p=0.06 95% CI -0.1, 8.8	t=1.1, df50 p=0.27 95% CI -5.1, 17.8
Greece	Refer to Appendix 8: Table 8.3.1				

Abbreviation: SCIM, Spinal Cord Independence Measure;
Statistical tests: U, Mann-Whitney U test; t, Independent t-test

Table 9.d.3.3: Differences in function between people, within each national group, with traumatic and non-traumatic injury

	Self-care (range 0-20)	**Respiration & sphincter management** (range 0-40)	**Mobility room and toilet** (range 0-10)	**Mobility indoor & outdoor** (range0-30)	**Total SCIM** (range 0-100)
USA	U=1097.5 p=0.24	U=1199 p=0.60	U=1218 p=0.65	t=-0.45, df120 p=0.65 95% CI -4.6, 2.8	t=-0.66, df120 p=0.51 95% CI -11.8, 5.9
UK	U=175.5 p=0.41	U=203.5 p=0.88	U=195.5 p=0.72	t=0.92, df50 p=0.35 95% CI -3.1, 8.4	U=187 p=0.59
Greece	Refer to Appendix 8: Table 8.3.3				

Abbreviation: SCIM, Spinal Cord Independence Measure;
Statistical tests: U, Mann-Whitney U test; t, Independent t-test

Table 9.d.3.4: Mean function scores for people, within each national group, with traumatic and non-traumatic cause of injury

	USA		UK	
	Traumatic mean±SD median min-max	**Non Traumatic** mean±SD median min-max	**Traumatic** mean±SD median min-max	**Non Traumatic** mean±SD median min-max
Self-care (range 0-20)	15.2±6.0 18, 0-20 n=95	17.3±3.2 18, 9-20 n=27	13.1±5.7 14.5, 0-20 n=42	14.5±5.9, 17 2-20, n=10
Respiration & sphincter management (range 0-40)	29.8±7.8 30, 0-40 n=95	29.6±6.0 30, 17-40 n=27	27.4±7.7 29.5, 11-40 n=42	28.0±8.2 28.5, 12-40 n=10
Mobility room and toilet (range 0-10)	8.0±3.4, 10 0-10, n=95	8.3±2.2, 10 2-10, n=27	7.5±3.5, 9 0-10, n=42	8.1±3.1, 9.5 0-10, n=10
Mobility indoor & outdoor (range 0-30)	13.7±8.9 12, 0-30 n=95	14.5±8.0 11, 4-30 n=27	13.3±8.2, 11.5, 0-30 n=42	10.6±8.2, 8 3-30, n=10
Total SCIM (range 0-100)	67.7±21.1 70, 3-100 n=95	69.7±13.7 71, 42-98 n=27	61.1±20.8 67.5, 18-91 n=42	61.2±19.7 61.5, 32-100 n=10

For Greece refer to Appendix 8: Table 8.3.3

Abbreviation: SCIM, Spinal Cord Independence Measure; SD, Standard Deviation

Table 9.d.3.5. Mean function scores for people, within each national group, with tetraplegia and paraplegia

	USA		UK	
	Tetraplegia mean±SD median min-max	**Paraplegia** mean±SD median min-max	**Tetraplegia** mean±SD median min-max	**Paraplegia** mean±SD median min-max
Self-care (range 0-20)	14.4±1.5, 15 0-20, n=31	18.0±2.4, 18 9-20, n=16	10.9±6.8 12.5, 0-20 n=28	15.3±3.9 17.5, 8-20 n=22
Respiration & sphincter management (range 0-40)	30.1±7.8, 30 15-40, n=63[1]	29.9±5.8 30.5 15-40, n=58	27.0±8.9, 29 11-40, n=42	29.3±5.5, 31 16-37, n=26[2]
Mobility room and toilet (range 0-10)	7.1±3.8, 9.5 0-10, n=64	9.1±1.6, 10 3-10, n=58	6.3±4.7, 8.5 0-10, n=22	8.7±1.7, 10 4-10, n=28
Mobility indoor & outdoor (range 0-30)	13.4±9.8 9.5, 0-30 n=64	14.3±7.2, 13 4-30, n=58	11.4±9.6 8.5, 0-30 n=22	13.7±6.9 12.5, 4-27 n=28
Total SCIM (range 0-100)	63.7±25.6 67.5 3-100, n=95	71.5±11.7 71, 42-96 n=58	55.6±25.6 61.5, 18-100 n=22	65.8±14.2 68, 32-90 n=28
For Greece refer to Appendix 8: Table 8.3.5				

[1]One outlier eliminated, [2]Two outliers eliminated;.
Abbreviation: SCIM, Spinal Cord Independence Measure; SD, Standard Deviation

Table 9.d.3.6: Interaction effect between the country of residency and gender on the cause or the level of injury

Subscales	Interaction effect of gender *country on DV	Interaction effect of cause of injury *country on DV	Interaction effect of type of injury *country on DV
Self-care (range 0-20)	F=1.55 p=0.021 η^2=0.00017 n=215	F=0.07 p=0.92 η^2=0.00008 n=219	F=0.56 p=0.57 η^2=0.0053 n=214
Respiration & sphincter management (range 0-40)	F=1.03 p=0.35 η^2=0.00057 n=215	F=0.59 p=0.55 η^2=0.00031 n=219	F=0.83 p=0.43 η^2=0.0003 n=214
Mobility room and toilet (range 0-10)	F=1.21 p=0.29 η^2=0.0014 n=215	F=0.05 p=0.95 η^2=0.00005 n=219	F=0.77 p=0.46 η^2=0.0008 n=217
Mobility indoor & outdoor (range 0-30)	F=1.48 p=0.22 η^2=0.00036 n=215	F=1.03 p=0.35 η^2=0.0024 n=219	F=0.79 p=0.45 η^2=0.0019 n=217
Total SCIM (range 0-100)	F=0.95 p=0.38 η^2=0.00077 n=215	F=0.49 p=0.61 η^2=0.00038 n=219	F=0.15 p=0.85 η^2=0.00012 n=217

Abbreviation: SCIM, Spinal Cord Independence Measure;
Statistical test: F, Two-way ANOVA

Table 9.d.3.7: Correlation between age or time since injury and function, within national groups[1]

	Age of respondent		Time since injury	
	USA	**UK**	**USA**	**UK**
Self-care (range 0-20)	r=-0.11 p=0.22 n=116	r=-0.01 p=0.292 n=50	r=0.065 p=0.48 n=121	r=-0.33 p≤0.01[2] n=52
Respiration & sphincter management (range 0-40)	r=0.04 p=0.65 n=116	r=-0.16 p=0.24 n=50	r=0.05 p=0.53 n=121	r=-0.13 p=0.23 n=52
Mobility room and toilet (range 0-10)	r=-0.13 p=0.13 n=116	r=0.13 p=0.34 n=50	r=-0.02 p=0.83 n=121	r=-0.08 p=0.54 n=52
Mobility indoor & outdoor (range 0-30)	r=-0.01 p=0.85 n=116	r=0.13 p=0.35 n=50	r=-0.15 p=0.08 n=121	r=-0.14 p=0.29 n=52
Total SCIM (range 0-100)	r=-0.07 p=0.43 n=116	r=0.13 p=0.94 n=50	r=-0.03 p=0.73 n=121	r=-0.23 p=0.09 n=52
Appendix 8: Figure 8.3.1				

[1]For Greek group refer to; [2] not significant post Bonferroni correction;
Abbreviation: SCIM, Spinal Cord Independence Measure;
Statistical tests: r, Pearson's correlation

Table 9.d.3.8: Mean function scores within males or females with and without pain across nations. Differences in the mean function scores within each gender per national groups

	USA Males			USA Females			UK Males		
	Yes mean±SD median min-max	**No** mean±SD median min-max	**Statistical test**	**Yes** mean±SD median min-max	**No** mean±SD median min-max	**Statistical test**	**Yes** mean±SD median min-max	**No** mean±SD median min-max	**Statistical test**
Self care (range 0-20)	16.8±4.7 19, 0-20 n=26	14.4±6.4 18, 0-20 n=55	t=-1.7, df79 p=0.09, 95% CI -5.2, 0.41	15.8±4.3, 18 3-20, n=18	17.1±43 19, 5-20 n=21	t=0.95, df37 p=0.34, 95% CI -1.4, 4.1	14.5±4.6 4.6, 7-20 n=11	13.4±6.3 8, 1-20 n=19	t=-0.51, df28 p=0.61, 95% CI 3.3, 3.0
Respiration & sphincter management (range 0-40)	33.5±5.4 33.5, 21-40 n=26	29.0±7.8 30, 0-40 n=55	t=-2.59, df79 p≤0.01[1] 95% CI -7.8, -1.0	26.8±7.3 26, 15-38 n=18	22.9±7.2 28, 15-40 n=21	t=1.3, df37 p=0.19, 95% CI -1.6, -7.8	26.9±6.2 27, 16-37 n=11	28.1±8.6 31, 11-40 n=19	t=0.40, df28 p=0.69, 95% CI -4.8, 7.2
Mobility room and toilet (range 0-10)	8.4±2.8 10, 0-10 n=26	7.3±3.7 9, 0-10 n=55	t=-1.3, df79 p=0.20, 95% CI -2.6, 0.58	8.9±2.0 10, 2-10 n=18	8.6±2.7 10, 2-10 n=21	t=0.4, df37 p=0.68, 95% CI -1.8, -1.2	8.2±2.8 10, 2-10 n=11	7.5±5.3 8, 0-10 n=19	t=-0.56, df28 p=0.57, 95% CI -3.2, 1.8
Mobility indoor & outdoor (range 0-30)	15.7±8.7 12.5, 3-30 n=26	12.6±8.8 9, 0-30 n=55	t=-1.47, df79 p=0.14, 95% CI -7.2, 1.0	13.7±8.3 15.5, 3-30 n=18	14.0±8.3 15, 3-30 n=21	t=0.10, df37 p=0.91, 95% CI -5.1, 5.6	16.7±8.3 18, 5-28 n=11	13.4±10.0 11, 3-30 n=19	t=-1.0, df28 p=0.32, 95% CI -10.2, 3.4
Total SCIM (range 0-100)	74.4±17.8 81, 29-100 n=26	63.4±23.2 68, 3-100 n=55	t=-2.1, df79 p=0.03* 95% CI -21.2, -0.7	65.2±16.9 65.5, 23-96 n=18	69.7±17.8 72, 25-100 n=21	t=0.79, df37 p=0.43, 95% CI -6.8, 15.7	66.4±17.7 73, 33-91 n=11	62.4±22.6 65, 18-100 n=19	t=-0.5, df28 p=0.62, 95% CI -3.9, 7.9

[1]not significant post Bonferroni correction; Staristical Tests: Independent t-test;
Abbreviation: SCIM, Spinal Cord Independence Measure; MSKP, Musculoskeletal Pain; SD, Standard Deviation

Table 9.d.3.8 continued: Mean function scores within males or females with and without pain across nations. Differences in the mean function scores within each gender per national groups

	UK Females			Greece Males			Greece Females		
	Yes mean±S median min-max	**No** mean±SD median min-max	**Statistical Test**	**Yes** mean±SD median min-max	**No** mean±SD median min-max	**Statistical test**	**Yes** mean±SD median min-max	**No** mean±SD median min-max	**Statistical test**
Self-care (range 0-20)	12.1±5.2 18, 2-19 n=11	12.9±6.6 15.5, 0-18 n=10	t=0.3, df19 p=0.75 95% CI -4.6, 6.2	11.5±5.9 10, 4-20 n=6	14.2±5.0 16, 2-20 n=15	U=33.5 p=0.36	16.0±5.4 19, 6-20 n=9	16.6±4.8 15.8, 8-20 n=8	U=33.5 p=0.79
Respiration & sphincter management (range 0-40)	26.4±8.7 29, 12-36 n=11	27.1±7.5 29, 15-37 n=10	t=0.2, df19 p=0.83, 95% CI -6.6, 8.1	32.1±11.6 38, 11-40 n=6	34.7±5.4 36, 22-40 n=15	U=40.0 p=0.69	33.3±9.6 38, 15-40 n=9	36.9±6.6 40, 21-40 n=8	U=18.0 p=0.07
Mobility room and toilet (range 0-10)	7.3±3.5 9, 0-10 n=11	7.3±4.0 9.5, 0-10 n=10	t=0.01, df19 p=0.98, 95% CI -3.4, 3.4	8.0±2.2, 8 6-10, n=6	8.8±2.0 10, 4-10 n=15	U=36.0 p=0.41	8.4±2.4 10, 4-10 n=9	8.1±2.3, 9 4-10, n=8	U=32.5 p=0.70
Mobility indoor & outdoor (range 0-30)	9.4±7.3 7, 0-26 n=11	10.9±6.6 12, 2-26 n=10	t=0.50, df19 p=0.62, 95% CI -4.8, 7.9	17.8±13.2 18.5, 1-30 n=6	20.9±8.0 23, 6-30 n=15	U=44.5 p=0.96	18.7±10.21 6, 0-30 n=9	21.2±9.7 26, 6-30 n=8	U=32.5 p=0.73
Total SCIM (range 0-100)	55.1±18.9 50, 32-91 n=11	58.2±21.8 65.5 18-82,n=10	t=0.35, df19 p=0.73, 95% CI -15.4,21.7,	68.8±28.9 75, 34-98 n=6	78.6±16.3 82, 44-95 n=15	U=41.0 p=0.75	76.4±25.48 2, 28-100 n=9	82.9±20.4 95.5, 45-99 n=8	U=32.5 p=0.73

Abbreviation: SCIM, Spinal Cord Independence Measure; MSKP, Musculoskeletal Pain; SD, Standard Deviation;
Statistical Tests: Independent t-test; Mann-Whitney U test

Table 9.d.3.9: Two-group differences on function, within male or females, for people with and without MSKP

	Total SCIM Male	Total SCIM Female
USA		
MSKP	t=-2.1, df79 p=0.03 95%CI -21.2, 0.7	t=0.79, df37 p=0.43 95%CI -6.8, 15.7
UK		
MSKP	t=-0.5, df28 p=0.62 95%CI -3.9, 7.9	t=0.35, df19 p=0.73 95%CI -15.4, 21.7
Greece	Refer back to Appendix 8: Table8.3.2	

Abbreviation: SCIM, Spinal Cord Independence Measure; MSKP, Musculoskeletal Pain.
Statistical tests: t, Independent t-test

9.d.4. SCIM III; relation to pain, LBP and MSKP

Table 9.d.4.1: Within national groups function scores reported by people with and without the pain categories

	USA Pain		UK Pain		USA Current LBP		UK Current LBP		USA MSKP		UK MSKP	
	Yes mean±SD median min-max	No mean±SD median min-max	Yes mean±SD median min-max	No mean±SD median min-max	Yes mean±SD median min-max	No mean±SD median min-max	Yes mean±SD median min-max	No mean±SD median min-max	Yes mean±SD median min-max	No mean±SD median min-max	Yes mean±SD median min-max	No mean±SD median min-max
Self care (range 0-20)	15.8±5.4 18, 0-20 n=117	13.9±7.3 16, 2-20 n=7	13.8±15.5 15.5, 0-20 n=50	2.5±0.7 2.5, 2-3 n=2	16.2±4.4 18, 1-20 n=77	15.5±6.7 18, 0-20 n=39	13.7±4.7 15, 2-20 n=36	12.5±7.9 17, 0-20 n=15	15.2±6.0 3, 0-20 n=44	16.4±4.5 18, 0-20 n=76	13.2±6.3 13.5, 2-20 n=22	13.3±5.0 16, 0-20 n=29
Respiration & sphincter management (range 0-40)	29.9±7.3 30, 0-40 n=115	27.6±9.3 40, 16-40 n=7	27.9±7.3, 29 11-40, n=50	14.0±1.4 14, 13-15 n=2	30.6±6.8 31, 15-40 n=77	29.2±6.9 28, 15-40 n=39	27.0±7.2 28.5, 11-37 n=36	28.0±9.1 30, 13-40 n=15	30.7±7.0 31, 15-40 n=44	29.7±6.9 30, 0-40 n=75[1]	26.6±7.4 27.5, 12-37 n=29	27.8±8.1 29, 11-40 n=22
Mobility room and toilet (range 0-10)	8.1±3.0 10, 0-40 n=115	6.9±4.7 10, 0-10 n=7	7.9±3.1, 9.5 0-10, n=50	0.0±0.0 n=2	8.3±2.6 10, 0-10 n=77	7.7±3.8 10, 0-10 n=39	8.1±2.7 9.5, 0-10 n=3	6.1±4.6, 8 0-10, n=15	8.6±2.6 10, 1-10 n=44	7.7±3.4 10, 0-10 n=76	7.7±3.2 9.5, 0-10 n=22	7.4±3.6 9, 0-10 n=29
Mobility indoor & outdoor (range 0-30)	13.9±8.6 12, 0-30 n=115	13.7±10.9 7, 3-30 n=7	13.2±8.1, 11 0-30, n=50	2.5±0.7 2.5, 2-3 n=2	14.5±8.4 15, 0-30 n=77	12.9±9.0 9, 3-30 n=39	13.2±7.3 11.5, 0-28 n=36	11.3±10.3 7, 2-30 n=15	14.9±8.5 14.5, 3-30 n=74	13.0±8.7 9.5, 0-30 n=76	13.0±8.5 11, 0-28 n=22	12.5±8.2 11, 2-30 n=29
Total SCIM (range 0-100)	67.7±20.1 70, 3-100 n=115	62.0±28.15 7, 26-100 n=7	62.8±18.9 66.5, 18-100 n=50	29.0±1.4 19, 18-20 n=2	70.2±17.3 70, 21-100 n=76[1]	65.0±22.4 69, 25-100 n=39	62.1±16.2 65.2, 32-91 n=36	57.9±28.9 65, 18-100 n=15	70.7±17.8 71, 23-100 n=44	65.9±21.9 69.5 3-100 n=75[1]	60.7±18.7 65, 32-91 n=22	60.9±22.1 65, 18-100 n=29

[1]One outlier eliminated;

Abbreviation: SCIM, Spinal Cord Independence Measure; LBP, Low Back Pain; MSKP, Musculoskeletal Pain; SD, Standard Deviation

9.d.5. SCIM III; relation to pain extent

Table 9.d.5.1: Correlation, within each national group, between function and the number of areas with pain. Interaction effect between country of residence and the number of areas with pain on function

Correlations	**Self-care subscale** (range 0-20)	**Respiration & sphincter management** (range 0-40)	**Mobility room & toilet** (range 0-10)	**Mobility indoor & outdoor** (range 0-30)	**Total SCIM** (range 0-100)
USA					
Areas of pain and function	r=-0.07 p=0.56, n=61	r=-0.13 p=0.31, n=61	r=0.14 p=0.38, n=61	r=0.03 p=0.80, n=61	r=-0.04 p=0.75, n=61
UK					
Areas of pain and function	r=-0.46 p≤0.01[1], n=28	r=0.01 p=0.93, n=28	r=-0.16 p=0.39, n=28	r=-0.26 p=0.18, n=28	r=-0.27 p=0.15, n=28
Greece	Refer to Appendix 8: Table 8.6.1				
Interaction effect of pain areas *country on DV	F=1.04, p=0.41 η^2=0.0008 n=118	F=0.40, p=0.95 η^2=0.0022 n=118	F=0.78, p=0.66 η^2=0.0071 n=118	F=1.84,p=0.051 η^2=0.0043 n=118	F=0.84, p=0.60 η^2=0.0055 n=118

[1]not significant post Bonferroni correction;
Abbreviation: SCIM, Spinal Cord Independence Measure;
Statistical tests: r, Pearson's correlation; F, Two-way ANOVA