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RESEARCH PAPER

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A qualitative exploration of living with chronic neuropathic pain after spinal cord injury: an Italian perspective

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ABSTRACT

Purpose: The purpose of this study is to understand how people with spinal cord injury (SCI) in Italy experienced and managed chronic neuropathic pain (CNP), and their perspectives of Italian healthcare services.

Method: Nine people with SCI participated. Two focus groups (three and four individuals) and one semi-structured interview were audio-recorded and transcribed. One “virtual interview” was conducted via e-mail. A qualitative thematic analysis was undertaken.

Results: Three main themes were identified. First, participants experienced pain as a powerful, intrusive and, at times, inescapable force, with the potential to overwhelm the sense of self, and place limits on enjoyable experiences. Second, participants recounted a strong desire to understand CNP, and, in the absence of expert guidance, used trial-and-error methods to find ways of relieving pain. Third, healthcare practice was perceived as pharmacologically focused and lacking specialist knowledge. Practitioners were described as reluctant to explore alternative therapies or participate in collaborative, patient-centred care.

Conclusions: This study reveals SCI-related CNP as a deeply troubling and psychologically distressing condition impacting widely on everyday life. Specialist, collaborative, individually tailored rehabilitation approaches that attend to patients’ priorities and experiences, include education about CNP, and offer opportunities to explore complementary treatments, may be welcomed by people living with this condition in Italy.

ARTICLE HISTORY

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Focus groups; qualitative methods; thematic analysis

► IMPLICATIONS FOR REHABILITATION

- People living in Italy with SCI-related CNP describe inadequate and ineffective pain relief.
- The impact of CNP on physical, psychological and social functioning is significant but may be an issue that continues to be underestimated by health professionals.
- Health professionals may better support patients living in Italy with SCI-related CNP by providing long-term, individualized, collaborative and specialist support.
- Ongoing, patient-led discussion forums where experiences, ideas and information can be shared may be useful to persons with SCI to help them cope with their pain over the long-term.


Introduction

Neuropathic pain is caused by a lesion or disease of the somatosensory nervous system.[1] Chronic neuropathic pain (CNP) affects at least 40% of people following spinal cord injury (SCI).[2–4] The mechanisms underlying CNP are multiple, vary across individuals and are not clearly understood.[5] Spontaneous or stimulus-provoked neuropathic pain following SCI may be experienced at the level of damage to the spinal cord or spinal roots, and may have both peripheral and central pain components, or below the level of damage, causing central pain as a result of damage to the spinal cord.[5]

CNP may occur from a few weeks to many months after SCI and is characterized by unpleasant and distressing sensations such as burning, shooting, squeezing, pins and needles, as well as painful cold.[5] Those who experience pain after SCI usually continue to experience long term severe pain which may worsen over time.[6,7] Pharmacological interventions remain the first-line treatment for chronic pain in general,[8] however, weak analgesic

potency, attenuation of effect and intolerable side effects contribute to inadequate efficacy.[9] In SCI-related CNP only approximately one third of people achieve a 50% reduction in CNP using the best available medications.[10] For most people, adequate pain control is difficult to achieve.[11] Pharmacological interventions, therefore, aim to provide sufficient pain relief to support function,[11] and yet may adversely affect mobility [12] as well as cognitive and psychological function,[13] the ability to work, and engagement in social activities.[13,14]

Pain is perceived as one of the most troubling consequences of SCI [7,15,16] directly contributing to disability, and adversely affecting quality of life.[17–19] Qualitative research has revealed the profound impact of SCI-related CNP on social, psychological and physical functioning.[13,14,20–22] These qualitative studies were conducted in Canada,[20,21] Sweden [14,22] and the UK,[13] where the management of chronic pain is informed from a biopsychosocial perspective. Nonetheless, dominant themes that were common among these various studies included poor pain control through medication failure, a lack of access to information about

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CNP and dependence upon personal resources rather than healthcare services for learning about CNP management.[14,20,21] Participants perceived healthcare professionals as heavily reliant on ineffective pharmacological interventions and unwilling to engage in dialog about other treatment and management options.[13,14] Participants also talked of clinicians' apparent lack of expertise and interest in pain management which further frustrated attempts to make sense of and cope with CNP in everyday life.[14] Complementary and alternative therapies were widely used, and reported as providing effective pain relief, at least in the short term.[14,20,22] A Dutch survey of 575 people with SCI, 69% of whom experienced neuropathic pain, reported that non-pharmacological treatments (e.g. exercise, physiotherapy, massage and relaxation) were more effective than pharmacological treatments for pain management.[4]

Spinal cord rehabilitation practices, organization, services and culture vary widely within Europe as well as in the rest of the world.[23] Chronic pain management strategies in general also demonstrate significant cultural variation across Europe.[24] In Italy, chronic pain management is a developing but emergent specialization in healthcare practice.[25,26] Italian healthcare professionals have reported uncertainty about integrating psychological and emotional aspects of patients' pain experience into practice, and have questioned whether patients' descriptions of their pain were a credible indicator of actual pain experience.[27] Practitioners in Italy have also voiced doubts about whether severe pain could be experienced in chronic non-cancer conditions.[26] Cultural and professional factors are thought to underpin these views.[26,27] Legislation, introduced between 1990 and 2010, obliged Italian healthcare institutions to establish pain management services, assure citizens' rights to pain treatment and simplified procedures restricting opioid prescription.[28,29] These laws also incorporated components of the biopsychosocial model, such as provision of individual care programs and active participation in decision making.[29]

Italian clinical guidelines for people with SCI advise a multidisciplinary approach for the treatment of pain in general but conversely only pharmacological, surgical and physical therapies are advocated for the treatment of neuropathic pain in SCI.[30] In contrast, UK,[31] Canadian [11] and Australian [32] guidelines recommend a holistic, multidisciplinary pain management approach based on education, cognitive-behavioural programs, self-management strategies, and physical and pharmacological interventions. These recommendations are aligned with a biopsychosocial approach that take into account a range of factors that contribute to an individual's pain experience which, at present, appears absent from Italian practice recommendations.

No qualitative studies have investigated the subjective experience of living with SCI-related CNP in Italy. This study aimed to explore how Italians with SCI-related CNP lived with their pain, what they knew about CNP, their experience of healthcare in Italy in the context of SCI and CNP, and how their pain was best managed within their particular health and personal contexts. The findings of this enquiry may offer insights to clinicians about the lived experience of SCI-related CNP that may have some positive impact on rehabilitation practices and services.

Materials and methods

Theoretical perspective

Qualitative research is a suitable means of exploring subjective experiences and the meanings individuals ascribe to the things that matter in their lives.[33] We took an inductive approach to

data collection and analysis [34] which allowed us to explore subjective meaning making. Guided by this approach, participants were encouraged to express themselves freely, and to focus on their priorities. We, therefore, aimed to ensure that the findings were embedded in the data and were not driven by established theories of pain experience, or our preconceptions about what might be important to participants in this study. Our methods were underpinned by a contextualist [35] and critical realist [36] position. We accepted participants' accounts of their lives and their pain experience as real, but also understood that these accounts were inevitably grounded in participants' perspectives and beliefs (critical realism). By taking a contextualist position, we acknowledged that by being co-constructed, inter-subjective and framed by both the researchers' and participants' personal, cultural, historical and social contexts, our findings are highly situated, local and provisional, and open to further interpretation. Nonetheless, the analysis offers a deep understanding of the topic which, via a process of vertical generalisability,[37] may challenge everyday assumptions and beliefs and, by doing so, generate important new knowledge.[38]

Research ethics procedures

The research protocol and all relevant materials (i.e. the participant information sheet, consent form and data collection methods) were approved by the University Research Ethics Committee in the UK, and the local research ethics committee of a SCI facility in Italy. All participants completed formal consent procedures prior to participating in the study, following procedures described below.

Participants

A purposive sample was recruited from records containing the names of SCI outpatients over 18 years old from a SCI unit in Italy, and diagnosed with CNP for more than 6 months. Exclusion criteria were medical, psychological or cognitive impairments that limited the ability to participate in focus groups or an interview. Twenty-five potential participants were contacted via postal services, and received detailed information about the study. As a part of the purposive sampling strategy, members of an independent SCI peer support group of former patients (10 people) were also invited to participate. Fifteen people responded of whom nine were eligible and agreed to participate (seven men and two women). Three people declined due to health problems, two people due to a lack of further interest, and one person was excluded as their chronic pain was not due to SCI.

Data collection

Following formal consent procedures, data were collected via two focus groups (FG) of three and four participants. A focus group is a form of group discussion which encourages participant interaction to explore and clarify different experiences, points of view and perspectives.[39] This method of data collection was chosen to support and facilitate discussion between participants emphasizing the value placed on their views and experiences, both positive and negative.[40] Furthermore, the informality, mutual support and friendliness of focus groups are thought to be a major advantage in working with potentially vulnerable groups.[41]

In addition, and according to preference, one face-to-face interview was undertaken, as well as one "virtual interview" via a series of email exchanges. A topic guide, developed on the basis of previous literature [14,20,21] was used in the focus groups

and interviews. It consisted of four open questions, and included probes and cues to encourage discussion.(Table 1) The first focus group acted as a pilot to check the utility of the topic guide, but as no changes were made to the content or structure of the guide, data from this focus group were incorporated into the final analysis.

The focus groups were moderated by VB who aimed to encourage a dialog among the group about scheduled topics, as well as unanticipated topics raised through interaction between the participants themselves. The moderator's role was to encourage participation, prompt elaboration and loosely guide the development of the discussion. A verbal summary of the discussion was provided at the end of each focus group and interview to ensure that the main points had been understood. Participants were given the opportunity to add comments by e-mail after the focus groups and interviews. One participant sent an e-mail elaborating upon a particular pain experience that was initially raised in one of the focus group.

The focus groups were composed of the principal investigator (V. B., moderator), the participants, a scribe who took notes on verbal and non-verbal expression and a second moderator (a head nurse) who offered logistical support and was on hand to deal with any unexpected events and interruptions.[40] The mean duration of the focus groups was 90 min. The face-to-face interview lasted 76 min, while the virtual interview consisted of four email exchanges. The first e-mail was composed of 1876 words while subsequent exchanges averaged 321 words which clarified aspects of the previous email. E-mail exchange stopped when answers were considered exhaustive by the principal investigator.

Table 1. Topic guide.

Questions	Potential probes
How does your pain affect your everyday life?	<ul style="list-style-type: none"> → Sleeping → Fatigue → Relationships → Work
What do you know about CNP?	<ul style="list-style-type: none"> → What is it for you? → How did you get the information you know?
How do you manage your pain? What makes it worse, what makes it better?	<ul style="list-style-type: none"> → Drugs: <ul style="list-style-type: none"> - Access - Helpful-always effective - Follow medical prescription - Self-medication - How do you deal with the quantity and the frequency? - Have you ever stopped by yourself? - Side effects? → Sleeping tablets → Other strategies: <ul style="list-style-type: none"> - What do you use/do? Acupuncture, exercise, massage, etc. - How did you find out about them? - Where did you go to find out about pain, help, management? → How long is the relief? - How does it help?
Is there anything else that you think would help you living with this sort of pain in your day-to-day life?	<ul style="list-style-type: none"> → Something that might have helped you that you weren't offered, or did not have access to? → Was there anything that was provided that you think was not necessary or that didn't help you in the day-to-day management of your condition?

Anonymised transcripts are available from the first author (V. B.) on request.

Data analysis

Data were collected in Italian, initial coding was undertaken in Italian, a second coding phase and thematic analysis was undertaken in English. Interview and focus group data were audio-taped and transcribed verbatim from voice recorders by the principal investigator (V. B.) and compared with written notes. During translation, Italian nuances and idiom that might be misunderstood if translated literally were explained and clarified to convey the correct contextual meaning.[42] Pseudonyms were assigned to participants and identifying details (such as place names) were changed to protect anonymity. A thematic analysis was then undertaken according to Braun and Clarke's framework.[34,43] Thematic analysis is a "method of identifying, analyzing, and reporting patterns (themes) within data".[34, p.79] From within our contextualist and critical realist position,[35,36] our analysis aimed to prioritise participants' perspectives and to illustrate their most relevant and pressing issues. Data were initially analyzed in turn, first the focus group data, followed by the interview data, then the virtual interview via email. After familiarization with the data (listening, transcribing, reading and re-reading, noting initial impressions), a further period of immersion in the data resulted in the generation of initial codes. Candidate themes were then identified from the codes, data were collated under each theme and reviewed for coherence. Checks of ambiguous comments and interactions were made with the scribe by comparison with the notes.[44] Initial codes and themes were compared across data sets and combined into common candidate themes with similar candidate themes clustered together to form the final major themes.

The principal investigator (V. B.) had a particular interest in SCI-related CNP based on her previous experience as a specialist physiotherapist in SCI rehabilitation in Italy. We expected that personal and cultural perspectives would inevitably impact the analysis, and we acknowledged that the principal investigator might share basic cultural assumptions with participants. A critical reflexive approach [45] was used by the research team to understand how cultural and professional assumptions may have shaped the analysis. A female, qualitative healthcare researcher and British neurophysiotherapist (E. C.), who had direct experience of working with people with SCI in the UK, and a specific interest in understanding the subjective experience of long-term neurological conditions, questioned the principal investigator's vision and understanding of the data through critical discussion of provisional themes. Two other British researchers, F. R. (health psychologist, qualitative researcher) and C. K. (neurophysiotherapist, mixed methods researcher), supported the writing up process by prompting further analysis of under-developed themes and arguments.

Results

The nine participants ranged in age from 32 to 75 years (median 52 years) and the time since injury ranged from 2 to 32 years (4 years). Consistent with the typical gender distribution for SCI,[46] there were more men than women in the sample (7:2). Table 2 provides participants' demographics and pain characteristics. Each participant described their pain in terms consistent with chronic neuropathic pain. Five participants described experiencing pain 24 h a day, 7 days a week. Six participants were taking analgesic medication at the time of the interview.

Table 2. Participant and pain characteristics.

Participant	Silvio FG1	Bruno FG1	Laura FG1	Marco FG 2	Alberto FG2	Carlo FG2	Omar FG2	Davide interview	Sara e-mail
Age	75	51	32	35	38	72	64	52	66
Gender	M	M	F	M	M	M	M	M	F
Occupation	Retired	Unemployed	Teacher	Qualified employed	Employed	Retired	Freelance	Employed	Retired
Marital status	M	D	U	U	U	M	D	M	M
Level of injury	T4-T6 ASIA B	L2-L3 ASIA C	L5 ASIA D	T6-T7 ASIA A	T8-T10 ASIA A	T10-T12	L3-S1 ASIA D	C6-C7 ASIA D	C5-C6 ASIA A
Time since injury (years)	4	32	2	3	8	3	2	8	10
First pain onset	2010	1981	2011	2010	2005	2010	2011	2013	2005
Pain distribution	Perineal area	Left hallux, external sides of feet	Right foot	Perineum, pelvis, abdomen, legs	Back, abdomen, left side of last rib	Abdomen	Both knees	Spine, abdomen, pelvis, legs	Thorax, abdomen, spine, pelvis, legs
Characteristics of pain	Burning	Pins and needles, stabbing, compression, hammered, twisting	Electric like pains	Burning, heaviness, pins and needles, evacuation sensation	Compression, stabbing, pins and needles	Compression	Burning, pumping	Burning, contusion, tingling allodynia	Compression, traction, electric like pain, needles, burning
Last day of pain	Day of interview	Day of interview	2 weeks before	Day before interview	Everyday	Everyday	Everyday	Everyday	Everyday
Number of days with pain in a week	6	7	1	5	7	7	7	7	7
Number of hours with pain in a day	9	24	6-7 (at night)	24	24	24 (worse at night)	24	24	5
Max pain level 0-10	7	10	8	9	9	6	8	7	8
Min pain level 0-10	4	2	0	1	4	3	4	2	3
Medication used	Lyrica (Pregabalin), Contramal (Tramadol)	Lyrica (Pregabalin), Citalopram, Oxycodone (Oxycodone), Lansoprazole, Hiacion, intrathecal Prialt (Ziconotide), Morfina (Morphine), Toradol (Ketorolac), Diclofenac	None	Lyrica (Pregabalin)	Lyrica (Pregabalin)	Lyrica (Pregabalin), Contramal (Tramadol)	Gabapentin	None	Lyrica (Pregabalin), Clonazepam

Mi: married; D: divorced; U, not married. Maximum and minimum pain rated by using a 0-10 numerical rating scale where 0: no pain and 10: worse pain imaginable.

Three overarching themes inferred from the analysis captured the most important concerns and experiences recounted by participants during data collection. The contents of each theme, and its relevance to the participants in this study, are presented below using written commentary and direct quotations selected for being the most powerful and illustrative of the topic. The first theme, "The continuous influence of pain in life", was dominant throughout the analysis, and focuses on the daily physical, psychological, emotional and social dimensions of the experience of pain. The second theme, "Constructing knowledge about living with CNP", focuses on participants' experiential acquisition of knowledge about ways of living with enduring chronic pain. These topics are explored in two subthemes: "Understanding CNP" and "Finding out what works". The final theme, "Developing specialist practice", conveys participants' perspectives about healthcare services and practice and how these might improve in order to meet the needs of people living with CNP following SCI.

Theme 1. The continuous influence of pain in life: "The biggest problem at the moment is suffering pain" (Marco)

CNP was reported to have a negative impact on all aspects of life such as relationships, work and leisure, physical and psychological well-being. It was regarded as the most significant issue in participants' lives. Indeed, for one participant, it exceeded the impact of the SCI itself. Participants described their pain, whether it was constant or not, as having the capacity to exert an almost total dominion over their thoughts and actions:

"It should be taken into account that one of the biggest disabilities is not losing the movement of the legs but having constant pain, having pain that does not allow you to move, does not give you the serenity to stay with others quietly or to do your job or other activities" (Bruno, constant pain all day, every day, FG1).

This quotation lays open the meaning of the physical, psychological and social disruption that underpinned the experience of CNP. Bruno described his pain experience as worse than the impact of his SCI. The pain constantly nags away at him, demanding attention. It is prohibitive and all powerful. He is uncomfortable at rest and finds no relief from movement. Whatever he does he cannot escape the pain or the impact of it in his life. Silvio, Davide, Laura and Sara below, also spoke of their pain as an intrusive and disturbing force in their everyday lives:

"I try to bear it [the pain], at a family level, with friends, I don't show it, and I keep my pain and I bear it. It's very hard, especially some days and during the evening". (Silvio, pain 6 days a week, FG1)

"The pain makes me tired. I arrive home [from work] and I'm really tired, so tired that during the week I go to bed at 8.30-9. I can't cope any longer". (Davide, constant pain, every day, interview)

"During the night, I only think of it [the pain], if I have pain it becomes a nightmare. I don't sleep anymore". (Laura, pain one day a week, FG1)

"[In the morning when I wake up] I already feel tired, and in a bad mood towards the coming day". (Sara, pain every day, e-mail exchange)

For these participants, pain enshrouded their daily lives. They described certain parts of the day as particularly distressing. Exhaustion from work, lack of sleep, disturbed sleep and the effort of shielding others from the impact of pain all took their toll. Marco spoke similarly:

"I don't wake up happy and therefore I know already that I'll be slower, that I'll be more nervous with relationships. During the day, I have, in my mind, focused on only that my day finishes as soon as possible. With my job, it is the day, I try to go back (home) as soon as possible, I try to avoid going out with friends" (Marco, constant pain, 5 days a week, FG2).

Pain affected Marco's attunement to the world. He not only spoke of the impact of pain on his physical self but also offered insight into how his response to pain was embodied through his tentative relations with others. Pain not only placed limits on his life as he struggled through work at high cost to his friendships and social relationships ("with my job it is the day"), but also placed limits on his capacity for joy and pleasure, hoping only that his day finished as soon as possible. A similar view was articulated by Sara:

"Slowly pain has removed the power to do things that I used to like and that distract me [from the pain] such as reading or painting" (Sara, pain every day, e-mail exchange)

It was not uncommon for participants to use absorbing activities such as reading or painting as a way of coping with pain nor was it unusual for participants to understand pain in adversarial terms such as those described by Sara and by Marco above. Sara places pain in the context of an adversary that in the past she could control through her participation in enjoyable activities. However, over time, she lost this sense of mastery. For Sara the pain "removed the power". She wants it understood that despite her best efforts the pain exerted its own agency and took away her control. Bruno spoke in similar terms. For him pain was an "itself", with the capacity to draw down his world, to close it off until the pain became the sole focus of his being:

"At a certain point, pain holds the power, it becomes so important that you cannot manage to think of anything else, it attracts all attention to itself" (Bruno, constant pain all day, every day, FG1).

In summary, the first overarching theme illustrated the enduring and intrusive effect of pain on everyday life. Participants described the ways in which CNP manifested itself, how CNP was perceived to disrupt daily actions and activities, and the times during which pain had the potential to overwhelm or hold sway over their sense of self and the things that mattered in their lives. For these participants, pain did not simply reside inside the body. It spilled out into the world, disturbing relationships with colleagues, friends and partners, constraining expectations and future possibilities. In this theme, participants described their pain and pain experience, and typically constructed pain as an independent agent or adversarial entity. Participants' sense of control over their pain was often in flux, but the threat of pain was a constant source of unease. The consequences on everyday life were significant and the potential impact on the sense of self-profound. The possibility of being lost in pain, as described by Bruno, called attention to his vulnerability, and sense of helplessness, and uncovered the deeply psychologically troubling experience of living with chronic neuropathic pain.

Theme 2. Constructing knowledge about living with CNP: "Thousands of experiments ... I'm continuously searching, I experiment on myself" (Marco)

Subtheme 1. Understanding CNP: "I discovered that there is an important emotional component of pain, not just physical" (Laura, intermittent pain, mainly at night, FG1)

Participants discussed working out what triggered their pain or made it worse, so that they could manage it as best they could in their day-to-day lives. Participants described low mood, negative thoughts, anger, stress and isolation as having the potential to increase the severity of CNP. Nonetheless, participants' pain experiences were deeply rooted in their individual personal contexts. They shared the experience of living with CNP but no common pattern, trigger or relief could be distilled from the accounts. Participants agreed, however, that pain and emotional well-being were tightly linked. In the following exchange from the second

Table 3. Positive/helpful and negative/unhelpful interventions and strategies.

Interventions and strategies found to be positive/helpful		Interventions and strategies found to be negative/unhelpful
Acupuncture	Being understood	Acupuncture
Sleeping tablets	Reading specialized information	Meeting with specialist pain consultant
Anti-pain drugs	Going out and social relationships	Being only focused on drugs
Lying down	Information from the Internet	Information from the Internet
Massage	Being distracted	Concentrating on pain
Tactile stimulation	Work in a non-stressful environment	TENS
Physical movement	Being busy	Massage
Gentle movements of the trunk	Going on holiday to hot places	Stopping medication
Stretching	Working on thoughts	Taking drugs
Prone position	Accepting pain	Intense physical activity
Diet	Sharing experiences	Swimming
Sport	Being positive	Maintaining still positions
Standing after eating	Hypnosis	Cannabis
Cannabis	Meditation	Inadequate information (quality and quantity)
Complementary therapies	Relaxation	

focus group, for example, Omar and Marco discuss how their mood altered their perception of pain:

"Does it happen to you that when you are angry pain worsens?" (Omar, constant pain everyday)

"No, it happens that usually if I'm stressed, if I'm mentally tired, effectively pain increases a bit" (Marco, constant pain, 5 days a week).

"It happens to me that a moment of anger, the phone call [at work], my instantaneous fury impacts me immediately, I feel the legs pumping" (Omar).

"You are right, it has often happened, that you transfer mood immediately, automatically" (Marco).

In this interaction, Omar and Marco described and agreed that in their experience, emotions such as anger or feeling stressed had a negative and proximate impact on their perception of pain *"my instantaneous fury impacts me immediately"* and *"you transfer mood immediately, automatically"*. Omar focused on the effect of anger whilst Marco focused on stress and fatigue. In a different example, Carlo ascribed low mood as having an adverse effect on his pain experience which then triggered negative thoughts about his future prospects:

"Pain increases because psychologically it brings me down, then I start to think about the future, what can I do with all these pains, what can I do?" (Carlo, constant pain, every day, FG2).

Davide had also come to understand the negative effects not only of his own low mood but also that of others, and in response he attempted to minimize the impact of low mood as a psychological strategy to help control his pain:

"I try to be always happy, I don't need sad people [around me], this is like a strategy" (Davide, constant pain, every day, interview).

Although not always possible, most participants agreed on the value of distraction, doing pleasant activities or being positive. These strategies helped participants to better tolerate and cope with the pain, and were developed or discovered overtime as they gradually learned to understand their pain. For example, Alberto described using strategies that worked to move his focus away from the pain:

"I managed to bypass it a bit ... trying to think and having my mind distracted on other things, because at the beginning I did not go out a lot ... I try to do many things ... in fact, with sport, I've already managed to take a good step". (Alberto, constant pain 24 h a day, FG2).

These exchanges and quotations illuminated the complex interaction between the impact of pain on psychological states, social

relationships and behaviours, and the impact of psychological and emotional well-being on the perception of pain and its effects on daily life. For the majority of participants, learning to understand CNP in terms of its impact on mood, and conversely the impact of mood on the perception of pain, seemed to be an important component of learning to live with CNP. Pain may provoke irritability, discomfort, social unease, withdrawal and fatigue, while anger, stress, isolation and low mood may increase the perception of pain. With respect to these accounts, CNP could, therefore, be understood as both the cause and the effect of negative emotional, psychological, social and physical functioning. A psychosocial understanding of CNP helps to convey the potential widespread effects of this condition. However, these psychosocial effects are experienced, made sense of and countered in highly personalized ways.

Subtheme 2. Finding out what works: "I did not engage in meditation but a kind of hypnosis, perhaps it gives a little bit of relief but two minutes later you are like before" (Marco)

Participants described engaging in a process of seeking out interventions or strategies that offered relief from their pain. What were regarded as positive interventions were described as those which helped control pain whereas those regarded as negative interventions tended to make the pain worse. These diverse interventions are identified in Table 3. Some interventions appear on both the positive and negative sides of Table 3, illustrating the idiosyncratic ways in which participants perceived the benefits or otherwise of these various trialed management and treatment strategies.

Most participants described struggling to access useful information about CNP from healthcare professionals. Apart from one participant who felt he had been offered adequate information, the majority of participants agreed that they were left to learn how to manage living with CNP by themselves. In their experience, doctors appeared unwilling or unable to provide useful or comprehensive information tailored to individual need:

"A bit from the internet, a bit from the doctors, always pulling with pliers" [an Italian expression to explain that information was difficult to access] (Bruno, constant pain all day, every day, FG1).

"If you don't ask, they [health care professionals] generally don't say ..." (Carlo, constant pain, every day, FG2).

"On the Internet, because where I was hospitalized, they didn't give me much information, they gave me Lyrica and Contramal [Tramadol], and then they told me, 'increase, decrease [the dosage], try'" (Alberto, constant pain 24 h a day, FG2).

"What is missed is firstly the lack of information because nobody knows or explains what neuropathic pain really is" (Marco, constant pain, 5 days a week, FG2)

"I never had the chance to have anything [about pain] explained to me" (Silvio, pain 6 days a week, FG1).

Information gathering, and learning about CNP from various sources formed an important strand of living with CNP, and may have held a particular significance in a situation where 'expert' knowledge seemed lacking.

Physical interventions generally involved techniques delivered by a healthcare professional such as acupuncture or massage. However, many management strategies were developed independently without the help of healthcare practitioners, such as tactile stimulation, stretching, relaxation, using particular positions or seeking out complementary therapies. Lacking consistent and knowledgeable guidance from healthcare practitioners, participants constructed knowledge about what worked for them through trial and error. Not all participants found strategies to help them cope with their pain. Nonetheless, even strategies that only offered short-term relief were described in positive terms:

"Maybe some positions on the wheelchair, pulling up a leg, reclining [the back] to the wall ... it seems that I have a bit of pain relief" (Marco, constant pain, 5 days a week, FG2).

"Stimulating some parts [of the body] that trigger pain, that increase pain, it provokes a stronger pain, and then after a light massage on the back, I relax and I'm nearly without pain, sometimes for hours" (Bruno, constant pain, 24 h a day, FG1).

"I did acupuncture, but it did not give me any benefit except temporary" (Alberto, constant pain, 24 h a day, FG2).

Treatment offered through specialist SCI facilities were described as primarily pharmacologically focused. Prescribed medication was characterized as both a positive and a negative intervention by most participants. The drugs had some positive effects on the pain but participants also reported several undesirable effects. For example, Alberto adjusted his prescribed dose not only because an increased dose had little further effect on his pain but also to control unpleasant side effects:

"I reduced the dose because I was not noticing pain relief and then to avoid feeling bad [from the side effects], I preferred to take it lighter and decrease it [the dose] slightly, not too much". (Alberto, constant pain, 24 h a day, FG2).

Other participants spoke about engaging in a similar balancing act:

"Increase, increase... I felt stunned, not in a confusion state but very sleepy, and I said 'I hold my pain', I prefer to hold the pain with me rather than be stunned". (Marco, constant pain, 5 days a week, FG2).

Several participants spoke of foregoing pain-relieving medication in exchange for a reduction in uncomfortable or poorly tolerated side effects. In weighing up the advantages and disadvantages of increasing his dose of prescribed drugs, Marco opted to perhaps retain some sense of control by living with pain, rather than gaining relief at the cost of blunting his everyday experiences through lethargy and fatigue.

Most participants used some form of prescribed medication to help control their pain. However, the focus group discussions and interviews illustrated that, for these participants, learning to understand the effects and manage the challenges that came alongside first-line pharmacological interventions was a significant feature of living with CNP. In the absence of expert guidance

from healthcare practitioners, participants made difficult decisions about self-medication which compromised pain relief in order to reduce the more undesirable effects of the drugs. Fundamentally, both prescribed drugs and alternative therapies were seen as palliative, with short-term effects, and when pain was at its worst no strategies or medications provided adequate relief.

Theme 3. Developing specialist practice: "They should be trained a bit more, and be a bit more empathetic". (Laura)

Participants offered their perspectives about healthcare improvements that might reduce the burden of living with CNP. Laura, (above, pain one day a week, FG1) and the majority of other participants, identified a lack of specialist knowledge in the doctors they encountered, and emphasized the need for a team approach, as well as alternatives to pharmacologically focused care:

"I have the feeling that they [clinicians] flail around in the dark" (Bruno, constant pain all day, every day, FG1)

"If there were two or three people of different types [of professional background] who treat pain, such as the physiotherapist, the nurse, the physiatrist, the specialist pain consultant". (Bruno)

"I don't understand why the only person in charge of treating neuropathic pain is the pain consultant, it means that you are going toward a way focused on medications". (Marco, constant pain, 5 days a week, FG2)

Participants understood that all interventions offered palliation rather than cure, but because of that most were interested in exploring all available options, including alternative therapies:

"In my opinion, alternative therapies should be proposed, at least suggested, when there is not a therapy that works well, therapies, such as acupuncture, maybe noninvasive; color therapy, or music therapy. They are all palliatives, but put altogether, sometimes offer the possibility of living better with your pain". (Bruno, constant pain all day, every day, FG1).

In the above quotations, Bruno (living with CNP for over 30 years) and Marco (living with CNP for less than five years) both advocated a comprehensive, individually tailored package of care, provided by a team of healthcare professionals. Alternative therapies were seen as a possible means to broaden out pain management programs beyond the confines of pharmacological interventions. These therapies were understood to offer the potential for living with the pain in a more positive way.

Improvements in the content of pain management interventions were valued alongside changes in the structure and approach towards care. For example, in the discussions, a high value was placed on building long-term therapeutic relationships:

"... continuity [of therapy] is very important. I think for pain the continuity to have someone that helps us to tolerate pain, doing these things [complementary therapy] unfortunately continuity was nearly impossible" (Carlo, constant pain, every day, FG2)

In contrast to the fragmented care that he had perhaps experienced, Carlo advocated for a coherent, long-term approach. Here, like Laura (above), he calls for a more empathetic approach to practice ("*someone that helps us to tolerate pain*") and provision of ongoing support to help manage the more troubling aspects of living with chronic pain. Sharing experiences with people living with the same condition was also thought to work along similar lines:

"It would be a good idea to organize in the SCI rehabilitation units a kind of mutual help group... supervised by one or more professionals that are interested in this subject". (Laura, pain one day a week, FG1)

Participants' discussions centred on developing a number of strategies to improve care. First, among these was the need for a

coherent philosophy of care that embraced multi-professional expertise in CNP for people after SCI. Other views included combining biomedical as well as complementary therapies, information giving and information exchange tailored to individual need, and the forging of long-term therapeutic relationships embedded in collaborative practice with the patient at the centre of care. These facets of care could be seen to constitute single tiles of a more complex mosaic of care that on their own may be fragmented and inadequate, but alongside other pain management interventions and strategies were seen by these participants to offer a more comprehensive, positive and effective package.

Discussion

Participants vividly described the stressful and debilitating experience of living with CNP following SCI. They discussed how they had come to make sense of their pain and, in the absence of expert advice, the strategies they had developed to best manage their pain and achieve some temporary relief. Pain was perceived to be a highly disabling part of their lives, taking primacy at times over the impact of the SCI itself.

Pain influenced many aspects of life including relationships, work, leisure and psychological well-being. CNP was a constant threat even in the absence of constant pain. It slowed people down, preoccupied them and precluded them from a range of interests and activities that would normally be of personal significance and importance. The severity and chronicity of their pain caused stress and anxiety as well as concern about present and future capacities and activities. Pain was augmented by low mood, anger, anxiety and negative thinking. At worst, CNP had the capacity to completely overwhelm participants' sense of their own existence. Our findings particularly emphasize that people living with CNP after SCI in Italy continue to struggle to pursue their lives in spite of their pain. While advances have been made in understanding the neurophysiological mechanisms underlying chronic pain,[5] our analysis emphasizes that a combination of physical, psychological, social and cultural factors all play a role in the experience of CNP for people living with SCI.

Participants worked to understand their pain and tried a range of strategies to alleviate their suffering. Participants' preoccupation with ineffective pharmacological interventions and their side effects, as well as their vigorous pursuit of alternative therapies resonate with findings from qualitative studies outside the Italian context.[13,14,20,21]

Consistent with the qualitative findings of Löfgren and Norrbrink,[14] participants described resorting to trial and error to work out coping mechanisms and interventions that helped them gain some sense of control over their pain. Even short-term interventions that offered temporary respite from the worst of the pain were positively evaluated by participants in the present study. The findings suggest that interventions and coping mechanisms were based on individual preferences and personal experience. Most strategies identified by participants were similar to those identified in previous studies.[14,20] However, in contrast to a dominant theme in the qualitative study by Henwood and Ellis,[20] there was little evidence that participants had effectively learned to live with their pain or accept it fully as a part of their lives. Henwood et al. [47] proposed a six-stage model of pain acceptance for SCI-related CNP which moved from initial stages where individuals tried to make sense of their pain and seek pain resolution, to later stages where pain permanence was acknowledged and pain was integrated into daily life using pain management strategies. Participants in the present study would seem to mostly fall into the first two stages of this model, but not the

latter pain acceptance stages. Henwood et al. [47] recruited participants who were similar to those in the present study (in terms of years since injury, gender, age and onset of CNP) and yet it is unclear whether these were a minority group of the Canadian SCI population who had learned to adjust to their pain, or importantly whether their multi-disciplinary care at a rehabilitation centre in Canada contributed to their ability to adjust more positively to living with CNP in comparison to the participants in the present study.

Clinicians in our study were not seen as very skilful or interested in listening to participants' concerns or offering interventions other than medication. Participants reported that their efforts towards making sense of their own condition were hindered by a lack of relevant or accessible information, and health care professionals who did not involve them, or facilitate an active role in their pain management. Isolated from expert sources of information and advice, participants were for the most part left to manage their suffering on their own. These findings confirm and extend previous qualitative studies that emphasized an overreliance on pharmacological interventions and a mismatch between the value placed by people living with SCI-related CNP on exploring alternative treatments and therapies, and the lack of interest they encountered from healthcare practitioners.[13,14,20–22] Moreover, the focus group discussions showed that participants were interested in working with more expert clinicians and a team of clinicians specialized in CNP. These new findings suggest that psychosocial interventions underpinned by a humanistic philosophy of care [48] could help people living with CNP after SCI to feel more informed and more in control of their pain, even if these interventions in themselves do not necessarily reduce the level of pain. The emergence of the potential value of sharing experiences with similar others is compatible with recommendations from other qualitative research in this field.[13,21,22,47] Self-help groups may be a useful means of increasing patient knowledge and awareness of CNP. The social component may help to reduce isolation and secure a stronger sense of well-being through being understood and listened to.

Participants in our study perceived the impact of CNP in everyday life to be underestimated and undertreated by healthcare practitioners. The findings from the present study provide further evidence of the potential value of taking a more humanistic stance towards the treatment and management of CNP after SCI in Italian healthcare contexts, and indeed, beyond. Consistent with recommendations made by Norman et al. [21] and others,[14,22] our findings emphasized the importance of listening to patients about their experience of pain and respecting patients' experiential expertise in managing and living with pain. Clinicians may consider adopting a pain management approach that not only focuses on reducing lived suffering by working with individuals to find the most effective pain relieving treatments, but also working at a personal level to support individuals living with CNP after SCI to thrive in ways that are meaningful for their ongoing lives, despite their ongoing pain experience. Self-help groups may present one positive way forward by providing space for mutual support, and to address the psychosocial issues associated with this condition. Rehabilitation practitioners may usefully look towards developing and supporting effective self-management programs, creating patient-centred information resources, and exploring meaningful strategies for living with pain. The direct involvement of clinicians from a range of different professions as well as people living with CNP after SCI is likely to be crucial for success.

In acknowledging the limitations of this study, the following points should be considered. A self-selecting sample may be limited by the inclusion of participants who find it easier to talk

about their health condition or who are simply more willing or able or well enough to participate, or those who feel particularly strongly about their experience and have something to say. The inclusion of a virtual interview via e-mail and a face-to-face interview enabled the inclusion of participants who were unable to travel to the focus groups. While this decision inevitably complicated the research process, these participants fulfilled the inclusion criteria and, on the basis of fair and equitable treatment, were included in the study. We could have considered using telephone focus groups so that all volunteers who met the inclusion criteria might have been able to participate in the same way. However, telephone focus groups may lack the richness of face-to-face interaction, and tend to be shorter which may restrict in-depth exploration of topics.[49] Other roles within the study could have been offered to these participants, for example by asking for their feedback on the interpretation and analysis of the focus group data; however, we saw their offers to participate as an opportunity to directly include individuals whose voices are not always heard. Consistent with previous studies,[13,14,20–22] the sample was heterogeneous in terms of pain distribution, and pain medications, but as with previous studies,[14,21] the majority of participants reported constant severe pain that they had endured for a number of years. Participants in this study were not coping with the immediate distress or disruption of SCI and it is possible that other aspects of their lives not explored in this study such as social standing and participation, financial security, personal resourcefulness and self-efficacy may have had some bearing on what was discussed. In this study, all but one participant attended the same outpatient unit in Italy. Nonetheless, Italian SCI Units are all provided with the same directives and guidelines; therefore, it is possible to assume that similar results might be found in other SCI Units in Italy. V. B. was involved in the rehabilitation of some participants at least 1 year before the study commenced but was no longer working with the participants at the time of data collection. While this arrangement reduced a possible conflict of interest, and minimized the participants' sense of obligation to take part, it may still have had some bearing on what was disclosed in the discussion. For example, participants may have been more forthcoming when working with a known researcher, but also perhaps may have offered only guarded responses to shield the researcher from negative feedback, or in response to a perceived power imbalance between themselves and a professional researcher. There is no direct evidence of this but it is impossible to tell if this was indeed the case. Reflexive approaches to data collection and analysis, through personal reflection about the influence of the researcher on the research, and discussions between V. B. and co-authors, worked dynamically to enrich the analysis, maintained the focus on the meanings constituted in the data and opened up new understandings.

The findings from this study cannot be generalized in any straightforward way. We are not claiming that the findings are representative of healthcare in Italy or the perspectives of all people living with SCI-related CNP. We also accept that researchers from different backgrounds may construct somewhat different findings. The value of this study lies in its contribution to a growing body of research in this field. This study resonates with, and amplifies, the findings of related qualitative studies.[13,14,20–22] These studies, using different theoretical perspectives, data collection methods and means of analysis, have nonetheless presented similar findings from participants in Sweden, the United Kingdom, Canada and now Italy. The themes are pervasive and it may be reasonable to assume that they capture something of the shared experience. This study deepens the understanding of the challenges of living with CNP after SCI. New voices from Italy have

shed light on the Italian perspective, but viewed alongside qualitative evidence from other parts of Europe and Canada, these voices strengthen the arguments for adopting a biopsychosocial approach for the care of people living with CNP after SCI. The context of this study has been described in detail so that healthcare practitioners may interrogate the findings presented here and use them to explore assumptions about their own practice, and, through a process of vertical generalizability,[37] perhaps find themselves better equipped to address the concerns and priorities of people living with CNP following SCI.

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Disclosure statement

The authors report no declarations of interest.

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