

THE INFLUENCE OF SOCIAL COMPARISON ON THE PERCEPTION OF  
QUALITY OF LIFE AMONGST PEOPLE LIVING WITH EPILEPSY IN IRAN  
AND THE UNITED KINGDOM

A thesis submitted for the degree of Doctor of Philosophy

By

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I, Aisan Ghaemian Oskouei, declare that the entire work in this thesis is mine and is written by myself. All the data demonstrated in this thesis is grounded in this original work. This research was carried out independently, and has not been submitted for any other degree.

## Abstract

Epileptic seizures are usually stressful episodes for individuals, not least as they are often experienced in public. Most research into epilepsy has been conducted in Western cultures, and we know little about the experiences of people with epilepsy and living in Middle Eastern countries. This study aims to examine the influence of social comparison on the perception of quality of life for people with epilepsy in Iran and in the United Kingdom.

Three studies were completed. Two studies were qualitative; exploring individuals' experiences of living with epilepsy and investigating coping strategies, respectively, (UK = 10, Iran = 10), for each study. Thematic analysis was used for data analysis. The third quantitative study was examined to determine whether social comparison dimensions, (upward negative, upward positive, downward negative, downward positive), predict quality of life in both countries, (N = 100 for each country), and a hierarchical multiple regression was used to analyse data.

The first study indicated people compare themselves to others and the unpredictable nature of a seizure causes individuals to perceive negative feelings and experience anxiety, furthermore urinary incontinence attached to seizures appeared to leave people feeling ashamed and anxious.

Study two revealed that whilst Iranian people used emotion-focused coping strategies, individuals from the United Kingdom applied problem-focused coping strategies.

In Iran religious coping strategies were used to cope with incontinency; however positive social comparison (downward) was used as a coping strategy for incontinency in the United Kingdom.

Study three found that self-esteem was the main predictor for quality of life in Iran and the United Kingdom. Whilst a seizure's severity negatively predicts quality of life in the United Kingdom, positive social comparison (upward) accounted for quality of life in Iran.

This study suggests that providing positive role models can help Iranians have a better perception for their quality of life, whereas British people potentially maximise their quality of life through seizure management.

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## CHAPTER 1: INTRODUCTION

### 1.0 Introduction

Chronic illnesses are the most prevalent worldwide health problems (Schulman-Green et al., 2012). Chronic illnesses lead individuals to seek healthcare, and they in turn could lead to disability and death (U.S. Centres for Disease Control and Prevention, 2011). Epilepsy has been considered a chronic illness with no specific cure (Baker, Baker, & Jacoby, 2013). It is recognised as one of the most important neurological chronic conditions in the world (Ngugi, Bottomley, Kleinschmidt, Sander, & Newton, 2010). According to the World Health Organisation (WHO), epilepsy has been estimated to affect almost 50 million people worldwide, with approximately 80% living in developing countries (WHO, 2010).

This thesis has focused on the role of social comparison in the perception of quality of life amongst people with epilepsy in two different countries, namely Iran and the United Kingdom. The Social Comparison Theory has been applied as the foundation of this study, which explains the natural tendency for individuals to self-evaluate by comparing themselves with others (Festinger, 1954), (more will be discussed in Chapter 3).

It is evident that, since epilepsy is a long-lasting illness, living with it can be both debilitating and demanding (Baker, 2002). This leaves individuals evaluating themselves by finding information and judging their own performance in life. In order to do this, an objective standard is required to judge peoples' performance and behaviour (Festinger, 1954), however because epilepsy is a chronic illness a standard of well-being is missing. Therefore the only way in which people with epilepsy can judge their own performance from information found, is to compare themselves with others. In addition individuals with epilepsy are faced with psychosocial limitations, uncertainty about their future and the fear of unpredictable seizures (Baker et al., 2013). The anxiety and uncertainty associated with epilepsy makes those suffering from it an appropriate context in which to investigate the social comparison processes.

Research has shown that chronically ill people have a poorer quality of life compared to the rest of the population, particularly in the case of epilepsy due to the long-lasting nature of the illness (Kerr, 2012). A perception of a lower quality of life for those with epilepsy has led to anxiety and an experience of negative psychological well-being (Kimiskidis & Valeta, 2012) along with lowered levels of self-esteem (Gauffin, Landtblom, & Rätty, 2010). However it is evident that social comparison as a mechanism affects the ways in which quality of life has been perceived in living with chronic illnesses (Arigo, Suls, & Smyth, 2014). As an example, the role of social comparison has been shown to be helpful for the Meniere's disease population; in a way positive interpretations were helpful in terms of perceiving a better quality of life (Dibb & Yardley, 2006). Additionally empirical findings indicate the role of comparison to other cancer patients has helped people find a positive perspective, enabling them to adjust to their illness (Bogart & Helgeson, 2000). More specifically, those who compared their own situation with fortunate others, found inspiration and hope (Bennenbroek, Buunk, van der Zee, & Grol, 2002). No studies conducted thus far have examined the social comparison process and its influence on the perception of quality of life with epilepsy; therefore this is the first attempt at examining the perception of quality of life amongst people living with epilepsy, and the effects that social comparison processes have on this perception.

The WHO emphasised the necessity of research for developing countries to add a better understanding of individuals' experiences in living with epilepsy (2010). Despite this report, currently there is limited knowledge about epilepsy in developing countries; particularly in Iran. It is documented that epilepsy has been recognised as one of the most common illnesses in Iran; the incidence of epilepsy in Iran is high, with 6% of the adult population having epilepsy (Sayemiri, Tavan, Sayemiri, Mohammadi, & Carson, 2014). Most research into epilepsy in Iran has focused on physiological perspectives and pharmacology therapy for epilepsy with little attention being given to the psychological point of view for epilepsy, particularly amongst the adult population (Valizadeh et al., 2013).

More importantly it is evident that the percentage of people with epilepsy in Iran is high, specifically in the central, eastern and northern parts of Iran (Sayemiri et al., 2014); therefore the need to explore more about the psychological status and factors



associated with the quality of life amongst the epileptic population in Iran has been recognised (Zamani, Shiva, Mohammadi, Gharaie, & Rezaei, 2014). People with epilepsy have a poor quality of life which highlights the negative attitudes and social barriers found within society; in addition social problems and marital dysfunction such as divorce is highest in Iran amongst people with epilepsy in comparison to the general population (Riasi, Rajabpour Sanati, & Ghaemi, 2014). It is reported that 54.8% of people living with epilepsy have divorced, which in turn affects an individual's perception of their overall quality of life.

In developed countries however a growing body of knowledge has contributed towards research into epilepsy (Ferro, 2011). The United Kingdom as a well-developed country has the required high standards of resources for chronically ill patients including those living with epilepsy.

Kerr, Nixon, and Angalakuditi (2011), for instance systematically reviewed the qualitative literature available for epilepsy studies in order to explore the impact of epilepsy amongst children and adult patients in the United Kingdom. They highlighted the major reduction of negative impact for epilepsy is due to individuals receiving sufficient medical support.

Therefore the United Kingdom's support system for individuals with epilepsy makes it an excellent context in which to investigate epilepsy in Iran, in order to compare it with the United Kingdom and to establish how Iranian people can benefit from the results of this comparison study.

Such knowledge could help Iranian health professionals to see how people with epilepsy are treated in different social contexts, such as that of the United Kingdom. This knowledge could also help the healthcare system in Iran from a psychological healthcare perspective to see which resources are available for the epileptic population in the Western world. For instance establishing supportive charities for people with epilepsy in Iran, where patients not only receive information and monthly magazines about their illness but also have the opportunity of discussing their issues with other patients.

The most important benefit of such supportive charities could be that they provide insight to the epileptic community by emphasising they are not the only ones living

with epilepsy, and there are in fact other people living with similar conditions within society.

However an important question remains; why this research has been carried out in a different social context? Research has shown that quality of life has been perceived in many ways in different social settings (Keith, 2001). Keith expanded on this and argued that considering a perception of quality of life applied in one specific culture and developing it in line with another cultural setting is misleading and ambiguous because the basic dimensions of quality of life are different from one society to the next (2001). Therefore the researcher will explore in what way quality of life is perceived in two dissimilar countries.

The justifications stated above provide the context for exploring the quality of life amongst people living with epilepsy, and examining the social comparisons which influence this perception in two different countries.

The key contribution of this thesis is to understand the social comparison process in the perception of quality of life amongst people living with epilepsy in Iran, as one of the Middle Eastern countries, and the United Kingdom, as one of the Western countries. Despite the role of social comparison and its influences on perceived quality of life in several chronic illnesses (Buunk & Gibbons, 2007; Dibb & Yardley, 2006), to the best of the researcher's knowledge, no studies have yet explored the role of social comparisons in epilepsy as a chronic illness. This highlights a need to investigate the role of comparisons in epilepsy to see how individuals with epilepsy compare themselves with others, in terms of self-evaluation and how they interpret health threats and perceive their quality of life. Therefore the researcher will contribute to the growing body of knowledge for examining the Social Comparison Theory in the neurological setting; particularly epilepsy to understand the ways in which people can perceive their quality of life.

Details of this whether the social comparison process is helpful or unhelpful could be beneficial for both individuals with epilepsy, and healthcare professionals in Iran and the United Kingdom because it could show how social comparison interpretations could play a substantial role in the perception of the quality of life amongst people with epilepsy. Knowledge of the interpretation into social comparisons could also

help individuals with epilepsy seek information about how others live with this chronic illness and how they manage their condition. In addition this knowledge could encourage medical professionals to provide their epileptic patients with some role models who could inspire them to feel similar to those role models. This will help to prevent the undesirable feelings consequential of negative interpretations of comparison, such as feeling down and disappointed (White, Langer, Yariv, & Welch IV, 2006).

Ultimately the researcher will contribute to the overall understanding of epilepsy from a psychological health perspective in Iran, where there is insufficient knowledge in this area.

## 1.1 Epilepsy

Epilepsy is the name given to a brain disorder, as defined by The International League Against Epilepsy (ILAE), as the recurrent (two or more) and unpredictable interruptions of normal brain function (Commission on Epidemiology and Prognosis ILAE, 1993). Febrile seizures referred to as a seizure in the first weeks of a new-born baby's life are excluded. In 1873 'the British Father of Neurology', Hughlins Jackson, formulated a definition of epilepsy as comprising of occasional, sudden, excessive, rapid and local discharges of grey matter. He described epilepsy as a recurrent, periodic, uncontrolled discharge of nerve tissue (Critchley & Critchley, 1998). The interruption of normal brain function is referred to as an epileptic seizure (Fisher et al., 2005). According to the International League Against Epilepsy (ILAE), the definition of epilepsy requires the occurrence of at least one epileptic seizure. In this regard because of abnormal, excessive activity in the brain an epileptic seizure is a short-lived occurrence of these symptoms. In the United Kingdom it is a common practice not to diagnose epilepsy or commence anti-epileptic drug treatment after a single seizure (Kwan & Sander, 2004).

### 1.1.1 Classification of Epileptic Seizures

The most noticeable symptoms of epilepsy are recurrent seizures. There are different types of seizures; Chadwick and Usiskin (1990) classify the specific types of epileptic seizures into two groups based on the location of onset, namely partial seizures and generalised seizures. Partial seizures happen in the localised part of the brain; however, there is no evidence of localised onset in generalised seizures. Each type of seizure can impact upon individuals in different ways.

A simple partial seizure occurs in a restricted part of one of the cerebral hemispheres with no impairment of consciousness; for instance the person is conscious but experiences a number of abnormal symptoms due to a damaged brain region (Chadwick & Usiskin, 1990). The complex partial seizure is the most common type of partial seizure and occurs in the temporal lobe. It is known as a ‘temporal lobe seizure’, which is associated with an alteration in consciousness (Chadwick & Usiskin, 1990). The person probably experiences hallucinations of sight, single sound, memory, taste or smell. In respect to memory, there are two short-lived disturbances of memory, which are common *déjà vu*, referring to a sense of familiarity in an unknown environment, and *jamais vu*, which refers to unfamiliar feelings in a known situation. In terms of gustatory and olfactory senses, they tend to be unpleasant and maybe accompanied by chewing movements and smacking of the lips (Scambler, 1989).

In generalised seizures the prevalence of two common seizures is observable *tonic-clonic* seizure and *absence seizure*, which occasionally are referred to as ‘Grand mal’ and ‘Petit mal’ respectively. Tonic-clonic seizures (grand mal) are generalised from the start where the person does not experience an aura, but loses consciousness immediately. The first phase is *tonic*, which causes muscles to contract and apparently if the person’s bladder is full, this contraction leads to urination. The tonic phase does not take more than a minute. This seizure is followed by a *clonic* or jerking phase, which may cause the person to bite one’s tongue (Chadwick & Usiskin, 1990).

Absence seizure (petit mal) was defined by Scambler (1989) as a childhood seizure that causes the individual to flutter their eyelids. Petit mal seizures occur very often during a day, where the person usually is unaware that anything has happened. Other generalised seizures are myoclonic and atonic seizures. Chadwick and Usiskin (1990) argue that these seizures involve an involuntary jerk which can affect the whole body. In these types of seizure there is no alteration in consciousness and the individual usually remains conscious.

### *1.1.2 Incidence*

Ngugi et al. (2011) systematically reviewed the prevalence of epilepsy worldwide and highlighted a significant difference in data collection methods between developing countries and the developed world. They mentioned that hospital databases have been more popular in developed countries, whereas community-based surveys are still common in developing regions. This research reported a significant contrast in the prevalence of epilepsy between developed and developing countries which is estimated as 4-7 per 1,000 persons and 5-74 per 1,000 persons, respectively. In addition in the United States, Banerjee, Filippi, and Hauser (2009) conducted a systematic review of the prevalence of epilepsy worldwide, and found prevalence rates of 6.8 - 5.2 per 1,000 in the North American population and 10.2 per 1,000 in the Turkish population. A European survey by Forsgren, Beghi, Oun, and Sillanpaa (2005) systematically reviewed the epidemiological studies of epilepsy in the adult population of different states within the European Union, and reported the prevalence range of 5.3 - 6.3 per 1,000 persons. Generally across the United Kingdom, the incidence of epilepsy was similar to that of Europe. There is evidence of individuals diagnosed with epilepsy in the United Kingdom of 190 per 100,000 in children with an age range of 0 - 4 years and 30.8 in the age range of 45 - 64 years (Heaney et al., 2002).

A recent study from the United Kingdom reported the prevalence of epilepsy to range between 4.2 and 9.0 per 1,000 people (Ferro, 2011). According to the Scottish Intercollegiate Guidelines Network (SIGN, 2015) there are 54,000 people with

epilepsy in Scotland and there will be between 2,000 and 3,500 new diagnoses each year.

It is reported that the prevalence and incidence of epilepsy across Middle Eastern countries, in particular the Arab regions is 724,500 individuals (Benamer & Grosset, 2009). The most recent study carried out in Iran reported the prevalence of epilepsy in Iran at 5%, with an estimated rate of 3% for people with epilepsy under 20 years old and 6% for individuals over 20 years (Sayemiri et al., 2014).

### *1.1.3 Etiology*

The cause of seizures and epilepsy can be found in previous studies which categorise the causes of unprovoked seizures into the following factors; endogenous factors, idiopathic (genetic), cryptogenic (unknown factors), infection and trauma (Chadwick & Usiskin, 1990; Gorji & Ghadiri, 2001). The WHO (2010) categorised epileptic seizures into; remote symptomatic, which refers to seizures that occur spontaneously as a result of a stroke and head trauma (provoked seizure); idiopathic seizures, which have a genetic basis; and cryptogenic seizures, which refer to unknown provoked seizures.

Endogenous factors mostly refer to febrile seizures in childhood. Such a form of seizure was described by Avicenna as, ‘an attack which usually occurs a short time after high fever in children under 7 years old’ (Gorji & Ghadiri, 2001, p. 457). The definition of idiopathic epilepsy is inherited epilepsy or genetic mutation (Chadwick & Usiskin, 1990). Recent studies have confirmed the most frequent causes of epilepsy were idiopathic (Oun, Haldre, & Magi, 2003). In addition infection and trauma have been identified as causal factors to developing epilepsy since they have an association with head injury and post-traumatic epilepsy (Chadwick & Usiskin, 1990). They further argued that when a person is diagnosed with epilepsy later in life, the etiology should be taken into consideration as the significant part of epilepsy management. This is because the diagnosis of epilepsy in adults should be identified based on clinical evidence (Chadwick & Usiskin, 1990).

## 1.2 Comorbidity of Epilepsy

Prior to reviewing the comorbidity of epilepsy, it is worthwhile providing a definition of comorbidity. In general comorbidity refers to co-occurrence of two or more chronic conditions in the same individual which is greater than coincidental (Gaitatzis, Trimble, & Sander, 2004; Téllez-Zenteno, Matijevic, & Wiebe, 2005). Individuals with epilepsy often experience more difficulties beyond the challenges of their seizures; therefore it is useful to take into account such challenges and consider them with required treatments (Jacoby, 2000). Previous research has highlighted the importance of comorbidity studies. A Canadian review for instance indicates that understanding the comorbidity of epilepsy appears to play an important role, due to the fact it assists patients with several chronic conditions to receive more healthcare benefits compared to those without multiple conditions associated with their illness (Téllez-Zenteno et al., 2005).

Although there are some comorbid conditions associated with epilepsy, such as alzheimer's disease, asthma, migraine (Gaitatzis et al., 2004) and stroke (Wannamaker, Wilson, Malek, & Selassie, 2015), the current review focuses on urinary incontinence as a comorbid clinical symptom of epilepsy. This is because in the published literature epilepsy has been associated with urinary incontinence in a Canadian study of Téllez-Zenteno et al. (2005). This may apply to those with epilepsy in Iran and the United Kingdom. Still whether this pattern emerges as associated factors for epilepsy in these two countries has yet to be confirmed.

### 1.2.1 Urinary Incontinence

The International Continence Society (ICS) defines urinary incontinence as 'the complaint of any involuntary loss of urine' (Sinclair & Ramsay, 2011, p. 143). This somatic issue has been classified into different types; *stress urinary incontinence*, which refers to leakage whilst sneezing or coughing; *nocturnal enuresis*, which refers to any unconscious passing of urine during sleep at night (Abrams et al., 2010) and *urge incontinence*, which is undesirable leakage associated with urgency (Sinclair & Ramsay, 2011). Urinary incontinence however has not been confined to these categories alone.

Suggestive evidence confirms that urinary incontinence can occur whilst the individual is unconscious during an epileptic seizure (Howell, Owen, & Chadwick, 1989).

Urinary incontinence has only received the attention of clinical diagnosis in epilepsy literature (Dworetzky et al., 2005; Timary et al., 2002; Brigo et al., 2013). Evidence for this is provided by a study of Téllez-Zenteno et al. (2005), who report that individuals with epilepsy may pass urine during an epileptic seizure. The prevalence of this clinical sign is five times more likely to be found in the epileptic population compared to those without epilepsy.

The comorbidity of urinary incontinence and epilepsy is well-documented (Dworetzky et al., 2005). Previous research has examined the various differences between epileptic seizure and non-epileptic seizure, Timary and colleagues (2002), highlight falling, tongue biting and urinary incontinence as the specific signs for epileptic seizures and specifically generalised tonic-clonic seizures in epilepsy. At least one of these typical signs of epileptic seizure was reported in their study by 60% of individuals with epilepsy, and 66% in both groups. Earlier a similar study (Peguero, Abou-Khalil, Fakhoury, & Mathews, 1995) found that 44% of individuals with epilepsy reported incontinence during their seizures. This was in line with a recent review (Brigo et al., 2013) which reported tongue-biting as a specific sign of epileptic seizures and urinary incontinence as an additional clinical sign of epileptic and non-epileptic seizures.

These studies indicate urinary incontinence as a clinical symptom of epilepsy. Still whether or not this symptom emerges as an associated factor with epilepsy in Iran and the United Kingdom has yet to be confirmed.

#### *1.2.1.1 Psychosocial Impact of Urinary Incontinence*

To date research has shown the psychological impact of urinary incontinence within the population. Bogner, Gallo, Swartz, and Ford (2002) for instance investigated the association of anxiety with urinary incontinence amongst community-dwelling adults



who were aged over 50 (n = 787). Participants were classified as a group of incontinent people who experienced the uncontrolled passing of urine for 12 months prior to their interviews. They reported that anxiety was perceived amongst those who were unable to engage in day-to-day activities as a consequence of urinary incontinence and it was also highlighted that urinary incontinence was associated with shame and withdrawal from society (Bogner et al., 2002). They suggested the early detection of urinary incontinence and the associated anxiety with incontinency may help to enhance individuals' well-being. Recently Molinuevo and Batista-Miranda (2012), found support for the psychological impact of urinary incontinence amongst the general population and highlighted that although urinary incontinence has not been considered a life-threatening issue, it may still have various psychological and psychosocial burdens on an individual's life, which may affect their psychological well-being. The attachment of shame and embarrassment to urinary incontinence is based on the nature of the issue which is uncontrollable and in turn may lead an individual to worry about the possibility of passing urine in public (Sinclair & Ramsay, 2011). This would be very distressing and upsetting (Ouslander & Abelson, 1990).

A similar study (Shaw, 2001) highlighted worry, distress and anxiety as the adverse consequences associated with urinary incontinence. This was because a failure to cure the incidence of urinary incontinence amongst adults led them to experience social isolation and poorer psychological well-being.

It should be acknowledged that much of the research on urinary incontinence has focused on the psychological impact of the condition within the general population, with much less known about the psychological effects of urinary incontinence as a clinical sign in epilepsy. To the best of the researcher's knowledge, no previous research has explored the psychological impact of this symptom in epilepsy. It should be noted that urinary incontinence in epilepsy may be distinct from incontinency in the general population; this may be because being incontinent is experienced only whilst having a seizure. The current research will contribute to filling this gap of knowledge in accordance with the psychological impact of urinary incontinence in individuals with epilepsy.

### 1.3 Psychosocial Impact of Epilepsy

The psychosocial impact of epilepsy has been well-documented (Hermann & Jacoby, 2009; Smith et al., 2009). Epilepsy as a chronic illness is linked to many social and psychological consequences; so many difficulties have been reported in living with this illness, such as anxiety (Jacoby, 2000), the effects of stigma (Baker, 2002), a lack of independence (Kerr et al., 2011), the inability to obtain a driving licence (Jacoby & Austin, 2007), feeling over-protected (Livneh, Wilson, Duchesneau, & Antonak, 2001), and a low socioeconomic status (Hosseini, Sharif, Ahmadi, & Zare, 2010).

Anxiety is defined as an emotional response to the anticipation of an unknown threat (Shahrokh & Hales, 2003). Anxiety is a reaction, such as apprehension and tension to internal or external stimuli which involves physical, emotional, behavioural and cognitive symptoms (Videbeck, 2013). Since epilepsy has been known as a complex neurological condition, the definition of anxiety might be different from that of the general population (Ekinci, 2011). Therefore it is useful to bring another possible classification for epilepsy orientated anxiety. There are several factors that can be associated with anxiety in epilepsy. Evidence for this is provided by Ekinci (2011), who has provided a classification of anxiety in epilepsy. The author suggests five associated factors of anxiety in the specific context of epilepsy:

- Neurobiological factors: the amygdala is the key construction in terms of producing symptoms of anxiety and is responsible for epileptic discharges in temporal lobe epilepsy (Beyenburg et al., 2001).
- Psychological factors: the unpredictable nature of seizures in epilepsy, and also fear of death are the related factors that cause patients with epilepsy to experience anxiety (Jacoby, Snape, & Baker 2005; Baker et al., 2005).
- Epilepsy related factors: seizure frequency has been associated with levels of anxiety; high levels of seizure frequency have been evident with the experiencing of anxiety amongst individuals with epilepsy (Adewuya & Ola, 2005; Kanner & Palac, 2002; Beyenburg, Mitchell, Schmidt, 2005).
- Age of diagnosis: the first onset of epileptic seizure in late life has been found as one of the key associated factors with perceived anxiety (Baker et al., 2001).

- The possible role of antiepileptic drugs (AED): research showed that side effects from some of the AEDs could in turn increase the risk of anxiety (Mula & Sander, 2007).

The unpredictable nature of epilepsy also has a negative effect on individual lives (Baker et al., 2013), which may lead an individual to experience anxiety (Gaitatzis et al., 2004). The authors systematically reviewed the prevalence of anxiety in epilepsy and reported that anxiety affects approximately 10 - 25% of people living with epilepsy. They emphasised the psychological consequences of this chronic illness and reported that 11% of those with epilepsy were diagnosed with anxiety each year (2004). Baker, Spector, McGrath, and Soteriou (2005), conducted research within the United Kingdom and examined the psychological influence of epilepsy amongst adolescents (N = 70). It was reported that individuals with epilepsy showed higher levels of depression and social anxiety than the control group (Baker et al., 2005). The psychological consequences amongst those with epilepsy were also documented in a study of Goldstein and Harden (2000). The authors stated that understanding the impact of anxiety in epilepsy will help to investigate the neurological and psychological mechanisms in epilepsy. Maroufi, Khomand, Ahmadiani, Alizadeh, and Gharibi (2014), found support for anxiety as a consequence of epilepsy amongst the Iranian population and stated that anxiety is not only a reaction to the illness; it may have a profound interaction with epilepsy. In addition Vazquez and Devinsky (2003), found support for anxiety as a consequence of the unpredictable nature of seizures in epilepsy. With regards to the social and psychological consequences of epilepsy, it is essential for researchers and clinicians to be mindful of the potential risk factors that could co-occur with epilepsy in some cases; as detailed above, most individuals with epilepsy experience difficulties beyond their seizures (Jacoby, 2000).

Generally speaking the aetiology of anxiety in epilepsy is unknown; however researchers have assumed that either the unpredictable nature of the seizures or the perceived loss of control, were possible causes (Jackson & Turkington, 2005). This can apply for a person with epilepsy in Iran and the United Kingdom, who may perceive anxiety as a result of an unexpected seizure.

The psychosocial impact of epilepsy is not only confined to anxiety; the effects of stigma can also be considered as psychosocial burden of living with epilepsy (Baker, 2002; Baker, Jacoby, & Gorry, 2005). Jacoby and colleagues (2005), in their review stated that epilepsy is not just a neurological illness but also it is a social label. The negative consequences of stigmatising the nature of epilepsy have also been evident in Iranian studies by Vanzan and Paladin (1992) and Valizadeh et al. (2013). Evidence for this is provided by Hosseini et al. (2010) research. They suggested that high illness concealment in Iran especially in the work environment is associated with the increased stigma attached to epilepsy. This was in line with an earlier study by Scambler and Hopkins (1980), who emphasised that peoples' careers were affected by their epilepsy, which led them to prefer to hide their illness from their employers. A study from the United Arab Emirates reported a high stigma attached to epilepsy (Muthaffar & Jan, 2014), which referred to the perception of epilepsy in public, where individuals still treat epilepsy as an evil spirit. This indicates that there is a misconception about epilepsy. This was confirmed by the WHO (2010), who reported a high prevalence of stigma attached to epilepsy in developing countries. Stigma has not been exclusive to Middle Eastern countries; European countries also highlighted stigma as an attached phenomenon to epilepsy. Taylor, Baker, and Jacoby (2011), recently highlighted the association of stigma and unemployment and their negative effects in the UK. The greater the stigma perceived, the lower the employment rate was reported. Reductions in social functioning as a consequence of stigma have also been evident in the study of Suurmeijer, Reuvekamp, and Aldenkamp (2001). They reported stigma in accordance with negative social functioning amongst the patients, such as recreational activities, which has in turn contributed significantly to their lives. Although in the United Kingdom the Disability Discrimination Act (DDA) in existence since 1995 can prevent people from any job discrimination (Gooding, 2000), nonetheless, seizure experience may result in social exclusion and unemployment (De Boer, Mula, & Sander, 2008). They emphasised the misconceptions surrounding epilepsy and stated that most epilepsy patients excluded from school, and employment commonly is disproved amongst adults with epilepsy. Earlier study confirmed that unemployment rates amongst people with epilepsy were twice that of the normal population (Elwes, Marshall, Beattie, & Newman, 1991), which, in turn, led them to experience social withdrawal. Barriers to find a secure job amongst individuals with

epilepsy were reported in similar recent studies (Bishop, 2004; Marinas et al., 2011). Similarly, Smeets, van Lierop, Vanhoutvin, Aldenkamp, and Nijhuis (2007) found support for the unemployment rate found amongst people with epilepsy. They systematically reviewed the literature and accordingly highlighted the psychosocial functioning impacts on predicting an employment rate for individuals with epilepsy, such as seizure severity, stigma and lowered self-esteem which, in turn, affects the job hunting prospect of a person with epilepsy.

In addition epilepsy can lead a person to demonstrate a reliance on others, and therefore the individual may end up living with no independence as a consequence (Baker, 2002). As an example, Livneh et al. (2001) expanded on this and highlighted epilepsy as resulting in a loss of independence which may in turn be associated with more housing limitations and driving restrictions. Inability to obtain a driving license has been evident in a study by Jacoby and Austin (2007). They highlighted that persons with epilepsy are subject to losing their driving license. They further suggested that people with epilepsy merit appropriate legislative support from DDA and European Union driving regulations. A lack of independence/autonomy was shown in previous research studies being dependent on others were associated with social limitations, such as freedom, unemployment and transportations (Bishop & Allen, 2003; Kerr et al., 2011).

There is an additional stress of living with epilepsy that is, feeling overprotected (Livneh et al., 2001). The authors emphasised this and stated that overprotective family and friends might act as life stressors which are triggered by epilepsy and could lead a person to have extra stress. A similar study highlighted the overprotective family members' role as psychological risk factors where they may provoke the level of anxiety in people with epilepsy (Gaitatzis et al., 2004).

In addition, socioeconomic status should not be neglected as one of the factors that can lead a person to have social functioning problems (Hosseini et al., 2010). Hosseini and colleagues carried out a qualitative study for individuals with epilepsy in Iran and reported that patients were subjected to various psychosocial consequences, which in turn were even more damaging than the epilepsy-related factors, such as the impact of seizure itself. They pointed out psychosocial issues, such as insufficient financial

support in society, and further stated that a lack of support led the patients to cover all the medication costs on their own. In line with this, Livneh and colleagues (2001), underlined inadequate financial support, as society's challenge for epilepsy patients. These studies documented the psychological/psychosocial impact of epilepsy, still whether these factors appear to affect those with epilepsy in Iran and the United Kingdom has yet to be determined.

#### 1.4 What Can Provoke an Epileptic Seizure?

Since the nature of a seizure is unpredictable, it is necessary to understand what can make a seizure more likely to happen; this will help with the primary prevention of developing an epileptic seizure (Dworetzky, Bromfield, Townsend, & Kang, 2010). There are so many factors that can make seizures more likely to occur amongst individuals with epilepsy. Earlier, Scambler (1989) termed these factors as *precipitants*, referring to 'short-term stimuli, such as exposure to television sets in susceptible people' (p. 7). The author suggested common precipitants, such as sleep deprivation, alcohol consumption, menstrual cycle and flashing lights. Precipitants may facilitate seizure to occur; however, they do not cause epilepsy itself (Malow, 2004). The author reviewed the association of sleep with seizure control in patients with epilepsy and stated that having insufficient sleep for example, can lead a person to develop a seizure. In a way, sleep deprivation provokes seizure episodes (2004). This was confirmed by a recent review of sleep disturbance amongst epilepsy patients (van Golde, Gutter, & de Weerd, 2011). The review highlighted the impact of sleep difficulties on daily functioning of patients, such as cognitive functioning and social functioning and behaviour. It was suggested that individuals with epilepsy are more likely to experience sleep disturbances, such as insomnia, which in turn it may provoke their seizure pattern (van Golde et al., 2011).

Alcohol consumption may also increase the risk of a seizure. Samokhvalov, Irving, Mohapatra, and Rehm (2010), systematically reviewed the literature available to explore the association of alcohol intake with epileptic seizures. They reported a majority of persons with epilepsy who were drinking alcohol, were subjected to

alcohol dependence. It is known that a seizure threshold can be elevated by alcohol consumption. In a way, alcohol is known to act in the brain and throughout its effect interrupts several mechanisms, which impact seizures' thresholds (Hillbom, Pieninkeroinen, & Leone, 2003). The association of alcohol abuse and individuals with epilepsy has been underlined in Western industrialised countries (Hillbom et al., 2003). However there is a lack of information in Middle Eastern countries, such as in Iran, which is centred on how alcohol consumption can impact on a person with epilepsy's general well-being, and whether their seizures are triggered by alcohol or not. This could be due to indications that Islamic countries are highly influenced and restricted by religious beliefs and Islamic rules against alcohol. This was confirmed by an Iranian study (Lankarani & Afshari, 2014), which highlighted the Islamic rules and alcohol prohibitions in the most Islamic countries. Sleep deprivation and alcohol consumption have been known as triggers for an epileptic seizure in the above studies. Nonetheless, these patterns emerge as the factors that make seizures more likely to occur amongst people living with epilepsy in Iran and the United Kingdom has yet to be confirmed. In addition, stress, excitement, fatigue and missing the medication are the other factors that can facilitate an epileptic seizure (Marlow, 2004). Notably, however, such triggers are beyond the scope of the current review.

## 1.5 Treatment of Epilepsy

Since epilepsy is one of the most common neurological illnesses, it is essential to use medication therapy for epilepsy treatment (Perucca & Tomson, 2011). Epilepsy treatments have been existing since a century ago, and it is dishonourable to leave epilepsy untreated (Perucca & Tomson, 2011). In Western countries, it is a common practice to prescribe AEDs, as the treatment of epilepsy after being subjected to two or more unprovoked seizures (Kwan & Sander, 2004). The impact of pharmacological treatment for epilepsy has been well-documented. Evidence for this is provided by a study in the United Kingdom (Moran et al., 2004); where the authors investigated the pattern of AEDs amongst 1,652 persons with epilepsy. It was reported the majority of their sample (68%) was on monotherapy (single course medication). Moran and colleagues highlighted the most commonly used medications were carbamazepine (37.4%), sodium valproate (35.7%), phenytoin (29.4%), primidone (14.2%) and lamotrigine (10.3%). Despite the existence of more than twenty AEDs available for

the treatment of epilepsy (Perucca & Tomson, 2011); yet, Moran et al. (2004), concluded that seizures remain uncontrolled amongst nearly 50% of epilepsy patients. However seizure remission was reported after changing the medication in 28% of individuals with epilepsy (Perucca & Tomson, 2011).

Epilepsy treatment is not confined to pharmacological treatments; there is a great deal of other suggested research on treatment, such as surgical treatment (Wiebe, Blume, Girvin, & Eliasziw, 2001), psychological therapy, namely cognitive behavioural therapy (CBT), (Ramaratnam, Baker, & Goldstein, 2005), and aromatherapy (Betts, 2003). However, the review of these treatment possibilities was beyond the scope of our current research.

### *1.5.1 Medication Side-effects*

It is known that AEDs are considered as the foundation for the treatment of epilepsy; however the importance of initial prescriptions of these medications should not be neglected (Perucca & Tomson, 2011). The authors expanded on this, stating that the final goal of the treatment process is the experience of being seizure free with no adverse medication effects. In this regard, medications should be directed to the specific seizure types and capability of the person to take the related medicine. Otherwise, the adverse medication effect on a person's well-being is irreparable (Perucca & Tomson, 2011).

In addition, AEDs' side-effects should not be neglected as they are associated with perceived damage in quality of life amongst those living with epilepsy (Kerr, 2012). In line with this, Ortinskia and Meador (2004) highlighted the AEDs' side effects on behavioural and cognitive development and stated that it is important to choose an appropriate course of treatment. This is because AEDs can alter the excitation levels of the nervous system, which commonly lead a person to experience cognitive impairment. The negative and positive effects of mood experiences were also reported (Ortinskia & Meador, 2004).



## 1.6 Conclusion

This chapter has illustrated the vision for the current thesis, which has specified the role of social comparison and its interpretation on the perception of quality of life amongst individuals with epilepsy in Iran and the United Kingdom. This chapter has also underlined the effect of social comparison as a process in other chronic illnesses, as this thesis will be contributing to the growing body of literature that social comparison can be applied to epilepsy as a chronic illness. The research rationale has been provided, followed by the key contribution of this thesis. Epilepsy definitions and classifications of the seizures have been highlighted in this chapter. In addition, the comorbidity of epilepsy has been discussed. This chapter also highlighted the current psychosocial factors associated with epilepsy. Further, the possible current treatment options, and medication and potential side-effects were emphasised in this chapter.

This thesis comprises of eight chapters. The next two chapters will illustrate quality of life and the Social Comparison Theory in a detailed explanation. Chapter 2 and Chapter 3 will outline the quality of life and social comparison constructs; they are outcome measures and are some of the main variables in this thesis. Subsequently, Chapter 4 provides a snapshot review of the first three chapters. The rationales for the methods used in this thesis and methodologies then are illustrated. Chapter 5, 6, and 7 are the three main studies involved in this thesis; these three chapters cover the two qualitative studies and one quantitative study, respectively. The individual rationales of these studies are provided in these chapters on a separate basis. Chapter 8 is the final chapter, which discusses all the findings of this thesis and covers them in accordance with the literature. Ultimately, the strengths and weaknesses of this research are provided and the study implications are discussed.

As this thesis investigates the factors affecting the quality of life for individuals with epilepsy in Iran and in the United Kingdom, the next chapter will demonstrate how quality of life can be influenced by certain factors. Although the main aim of this study is to examine the influence of social comparison, Chapter 2 focuses on defining the quality of life construct which is the main outcome measure in this thesis.

## CHAPTER 2: QUALITY OF LIFE

### 2.1 Introduction

Following the previous chapter, the first section of this chapter presents the available definitions for the quality of life construct. It highlights quality of life and its difference with health related quality of life. This chapter also covers the impact of neurological illnesses, such as epilepsy on perceived quality of life. In addition, this chapter accents the theoretical frameworks of the thesis. The last part of this chapter examines how other influencing factors, such as demographic characteristics, physical variable (seizure severity), and psychological variables, (self-esteem and anxiety), can affect quality of life. It will be followed with adjustment processes, and coping strategies for improved quality of life. Finally the conclusion presents the general definition for quality of life drawn from literature.

### 2.2 Definition

Quality of life as a construct has been applied to life satisfaction which has been associated with hierarchical need satisfaction levels of physiological, safety, belongingness, love and self-actualization (Maslow, 1954). Recently Veenhoven (2001), linked quality of life to quality of living environment, quality of performance and how well individuals manage. Veenhoven (2001), also attributed quality of life to happiness as subjective satisfaction of life, and quoted that ‘good life must be a happy life’ (p. 1). Other researchers have made an association between quality of life and goal achievement (Kuijjer & De Ridder, 2003), where individuals perceive a better quality of life if they feel they achieve their goals. More importantly, researchers have defined quality of life in different ways and have focused on different aspects, such as psychological, social and physical well-being (Murrell, 1999; Haas, 1999); in a way, quality of life of the person should be assessed within their social context (Murrell, 1999). The author expanded on this by further explaining quality of life as a key concept in neurological settings that have been almost underdeveloped (1999). In addition, Jacoby (2000), defines quality of life in epilepsy as a multi-dimensional construct that includes social, psychological and physical domains. This thesis also

emphasises on the subjective perception of quality of life which covers physical, psychological and social domains.

Murrell (1999), distinguished two approaches in quality of life definitions; the person-centred approach (subjective state), and the health-based approach (objective state). Looking at these two distinct approaches in the definition of quality of life, it is evident why quality of life has diverse definitions. The subjective state is a holistic approach which involves both physical and psychological well-being of the patient. It mostly refers to a subjective experience and subjective interpretation of an event. In this approach quality of life is, 'that which the patient says it is,' (Joyce, 1994, p.47). Subjective quality of life was split into subjective well-being and psychological well-being, where the former one refers to life satisfaction and happiness, and the latter one is engaged in individual development, (Keyes, Shmotkin, & Ryff, 2002). However, the objective aspect follows the physical well-being and a medical approach, which provides the numerical manifestation of the patient, instead of reflecting the actual patient's quality of life (Murrell, 1999). For example, looking at the long-term consequences of neurological illnesses would explain why the health-based approach (objective state), has been insufficient in explaining the quality of life domains. This is because the nature of a neurological illness is chronic and consists of fluctuations of emotional and physical functioning where all these factors are foundations of an experience of a neurological illness. Therefore, the objective state, on its own, has failed to determine the regular improvements and achievements met at the individual level which, in turn, affects the individual's perception of quality of life (Murrell, 1999). On the other hand, the subjective state has more focused on individual experiences, since the contributory factors to perceive quality of life, either as good or bad, are personalised and different from person to person. As a result, both subjective and objective states of quality of life must be considered in quality of life assessment (Murrell, 1999).

There has been confusion in defining quality of life and the health related quality of life (HRQOL), which are often used interchangeably in some research (Haas, 1999). Haas criticised the term quality of life for being too broad to be used in healthcare research. Hence the global quality of life needs to be distinguished from HRQOL (1999), suggesting that the term HRQOL is better owing to the fact it directly refers

to health-related circumstances. This is because there are other aspects of life, not necessarily referring to health, such as income, freedom and environment that also impacts quality of life. Jacoby (2000), emphasised on this in her review of the topic by referring to the debate in an international workshop in 1991, which stated that quality of life covers a multi-dimensional concept of an individual's experience, where these dimensions are not certainly grounded in health and medical aspects. Jacoby, however, argued that researchers in the field of health services sometimes tend to focus on HRQOL rather than quality of life itself as what they are mostly concerned with is assessing dimensions in quality of life that are related to medical care and health (2000).

The WHO defines quality of life as, 'an individual's perception 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.' (WHOQOL Group,1993, p.153). This definition is a considers quality of life as a broad concept, in which a person may be influenced by physical health, social relationships, psychological state and levels of independence, and individuals' relationship to their living context (WHO, 1993). Later, Baker (2001), in his review of the literature, argued that quality of life can be defined as a person's emotional reaction to their life situations, and also their capability to meet their personal requirements. Similarly, Bishop (2005), reviewed the quality of life and psychosocial adaptation to chronic illness and disability, and defined quality of life as the subjective well-being which is drawn from a person's evaluation of satisfaction with a combined personal and clinical domain (Bishop, 2005). Bishop conceptualised quality of life, indicating that overall quality of life is linked to life satisfaction covered through specific areas of life (2005).

The cultural context is another important aspect that should be taken into account in defining quality of life. Carr and Higginson (2001), contend that the concept of quality of life might be different between individuals in different cultures; this is because some cultural or social factors may affect their evaluation of quality of life. For example, a study of quality of life perceptions amongst elderly people within twenty-two countries with different cultural backgrounds by Molzahn, Kalfoss, Makaroff, and Skevington (2011), showed significant differences in the diverse aspects of the perceived quality of life amongst individuals across the countries. This was a cross-

sectional study, where it was reported that culture described 15.9% of the variance in the significance ratings of perceived quality of life. Molzahn and colleagues conclude that individuals in developing countries evaluated their overall health status and physical domain of perceived quality of life more than those in developed countries. In addition, receiving financial support and social care were more reported amongst individuals in developing countries than those in the developed countries (2011). Similarly, the concept of quality of life contributed to physical fitness, survival, social status, family life and equality in the low income countries (Skevington, 2009).

In general, Betts (2000), highlighted the importance of quality of life studies and related measurements as a tool which can be used to improve understanding of the patient's life. Used effectively, this tool could provide physicians with a useful view of what is the best treatment or therapy to be delivered.

Taken together, based on the previous definitions, this thesis defines quality of life as the subjective perception of the impact of epilepsy, as a neurological illness, on individuals and is underpinned by multiple dimensions; the physical, psychological and social aspects (Cramer et al., 1998; Cramer, 2002). This thesis adopts the position that quality of life is linked with not only health but also the physical, psychological and social functioning, which takes into account the subjective aspects of quality of life.

### **2.3 Theoretical Aspects of Quality of Life**

In order to understand what quality of life is, it is required to see the theoretical underpinning of the quality of life models. Therefore, some quality of life theories have focused on need satisfaction (Maslow, 1954), happiness achievement and goal satisfaction (Allport, 1937); however, these fail to explain the psychological consequences of living with a chronic illness and their influences on quality of life. Two main theories of quality of life are reviewed below; referring to how psychological and social dimensions can affect quality of life after a physical handicap: A Patient Based Health-Related Quality of Life Model in Epilepsy (Baker, Smith, Dewey, Jacoby, & Chadwick, 1993) and the Biopsychosocial Model (Engel,

1977). These two theories provide a related framework for exploring the compound interaction between the domains, the importance of which demonstrates how quality of life is defined in this study through the physical, psychological and social domains of an illness.

### *2.3.1 A Patient-Based Health-Related Quality of Life Model in Epilepsy*

Baker et al. (1993), proposed the Patient-Based Health-Related Quality of Life Model in Epilepsy which explains the link between physical, social and psychological manifestations of an illness and their impact on well-being and quality of life for individuals living with epilepsy. This was the first attempt at developing the HRQOL model in epilepsy in accordance with the WHO definition of quality of life to include the major domains of quality of life that are related to physical, psychological and social issues (WHO, 1947). The model was examined amongst the residents from the United Kingdom. They measured three domains: 1) physical domains, (seizure frequency, seizure severity, general health and activities of daily living); 2) social domains (housing condition, occupation, finance, marital functioning, leisure and social activities, contact with friends and neighbours, child and parent interaction as well as legal matters); and 3) psychological domains (mood: anxiety and depression, and psychological coping resources). This was a cross-sectional questionnaire study which indicated that factors in the psychological domains, (depression, anxiety, happiness, overall mood, self-esteem, mastery), were highly and positively inter-correlated. This signified the practical construct of psychological well-being in epilepsy. However physical domain factors were not correlated, which indicates that seizure frequency and seizure severity should be measured separately (Baker et al., 1993). In addition, this model was a patient-perceived HRQOL model, which provided people with perceptions of their expectations and accordingly filled the gap between their actual and preferred quality of life. Although this framework allows the relationship between physical, social and psychological well-being in living to be examined alongside epilepsy, the nature of the study was not longitudinal. Therefore, search for causality of the variables were almost impossible (Baker et al., 1993).

The model proposed the complex interaction between physical, psychological and social aspects, where these interactions have significant impact on the quality of life of a person with epilepsy (Baker et al., 1993). In this regard, Baker and colleagues stated that anxiety as the common psychological disturbance has a foundation in the unpredictability of a seizure. Depression may be experienced as a result of constant anxiety. Lower levels of self-esteem may be perceived due to unemployment, and perceived stigma as well as an over-protected family. They concluded that, when looking at the complex interaction between these three mentioned domains, the lack of a comprehensive quality of life model for epilepsy can be explained; however it should be noted that the social domains were difficult to assess, as the measure had low internal consistency in the study population (Baker et al., 1993). Though, this model represents an important foundation for the current study, it has similarities, as it measured three relevant domains, (physical, psychological and social), and highlighted the complex interaction of these domains in the quality of life of individuals living with epilepsy. In a way, a person with epilepsy has physical handicaps, (seizure severity), and this factor is unable to determine the quality of life of the person on its own. Thus other factors might be required to see how the quality of life of the person with epilepsy is affected.

### *2.3.2 The Biopsychosocial Model*

The biopsychosocial model incorporates biological, psychological and social domains of an illness which are proposed to have significant role in patients' functioning and quality of life (Engel, 1977). The biopsychosocial model provides opportunity to understand the basis of an illness and healthcare patterns in social context in which the person lives, in collaboration with psychological considerations (Engel, 1977). In addition, this model has been a good foundation for health psychologists' conceptual framework as it explains how the illness can be understood in combination of physical, psychological and social domains (Schwartz, 1982; Suls & Rothman, 2004). Previous researchers have acknowledged the value of the biopsychosocial perspective and indicated that how biological, psychological and social aspects have interacted to affect the health outcome (Smith & Ruiz, 2002): for example, Anderson (2002) reported stress reduction as the main psychological intervention to boost the quality

of life amongst adult cancer patients. Anderson, systematically reviewed the experimental and psychological interventions studies and underlined emotional distress and fatigue as the most common complains of cancer patients, which in turn these difficulties led to decreased quality of life; however, psychological interventions, such as cognitive-behaviour therapy (CBT), relaxation training have significant impact on cancer patients' quality of life (2002). In addition, Suls and Rothman (2004), conclude the recognition of the interaction between physical, psychological and social aspects not only is the main foundation of the biopsychosocial model for health psychologist it also helps clinical practitioners to maximise their medical diagnosis and better predict their treatment.

The biopsychosocial model has also been applied in epilepsy as a chronic neurological condition (Elliot & Richardson, 2014). They examined this theory amongst the Canadian population. They hypothesised that the psychological and social factors would explain quality of life, more than biomedical factors. Elliot and Richardson measured and assessed the biological-biomedical aspects (age, age at epilepsy diagnosis, somatic comorbid condition such as asthma, diabetics, arthritis, hypertension, heart disease and stroke); psychological aspects (anxiety, self-perceived life stress, mental healthcare utilisation); and social aspects (education, employment, income and marital status). This was a cross-sectional questionnaire study which indicated that all the three aspects were highly correlated. They found that the biopsychosocial model contributed significantly more than biomedical domains, as it provided more comprehensive view. Specifically, psychological and social domains account for more variance in quality of life, in comparison to biomedical domains. Elliot and Richardson (2014) suggest that biological-biomedical domain, (seizure severity), has limited influence on quality of life; where the explained variance of this domain was dramatically decreased when psychological and social domains were controlled. In addition, Lu and Elliott (2012), found support for the biopsychosocial model in epilepsy and argued that limited activity and insufficient social support accounted for more variance than a seizure itself, which predicted poorer mental health amongst epilepsy patients. This is important in line with the current study as it adds additional support to the significant impact of psychological and social domains on quality of life of people with epilepsy. Based on the assumption that a person's overall



quality of life in living with epilepsy has not been directly affected by the illness itself, (physical domain), the biopsychosocial model offers an explanation for how indirect factors could affect the person's quality of life which reflects the pressure triggered by personal, psychological and social resources, such as unemployment, decreased self-esteem and a lack of income (Suurmeijer et al., 2001). It is known that those with epilepsy mostly complain about psychological handicaps, more than physical issues. 'Epilepsy is much more than seizures' (Elliot & Richardson, 2014, p.62). This is in line with the Patient-Based HRQOL model in epilepsy proposed by Baker et al. (1993) emphasised on the importance of psychological and social effects on quality of life amongst people living with epilepsy. Despite the medical findings, there is not adequate literature in the field of psychology and psychosocial aspect of epilepsy (Jacoby, 2002). The necessity of exploring a link between psychosocial problem and epilepsy and their effects on quality of life, have been well documented (Bishop, Berven, Hermann, & Chan, 2002). This assumption is reflected in the approach of the present study, where the biopsychosocial model applies to people with chronic illness, such as epilepsy (Suurmeijer et al., 2001).

Overall, the Patient-Based Health-Related Quality of Life Model in Epilepsy and the biopsychosocial model underpin the foundation of the definition of quality of life in the current study, which refers to subjective perception of quality of life.

## **2.4 Impact of Epilepsy on Quality of Life**

As mentioned in Chapter 1, epilepsy has been considered as a chronic illness; where a person once diagnosed with an illness, has to live with it for the rest of their life. Although this classic definition does not fully explain the reality of life with a chronic illness, a long-lasting illness, which is not intended to be cured and most likely is a residual condition (Stanton, Revenson, & Tennen, 2007). There is evidence which suggests that epilepsy, as a neurological illness, can have a destructive effect on quality of life because the illness is chronic (Kerr, 2012), particularly so, as there is no proper cure for epilepsy and therapy is likely to be continuous. It is necessary therefore to consider quality of life as a substantial healthcare outcome (Jacoby, 1992).

The quality of life in epilepsy research has mostly focused on the HRQOL (Jacoby, 2000), as the impact of epilepsy on quality of life is multidimensional (Bishop & Allen, 2003), where the HRQOL construct in epilepsy covers physical, psychological, and social status (Taylor, Sander, Taylor, & Baker, 2011), and all these domains are influenced by epilepsy.

Experience of seizures and their frequency has a detrimental effect on quality of life for a person with epilepsy (Leidy, Elixhauser, Vickrey, Means, & Willian, 1999). Evidence of seizure impact and how it can affect quality of life was found in a study amongst people with epilepsy in the United Kingdom (Moran et al., 2004). This was a cross-sectional study, where the clinical characteristics of epilepsy were examined. It was found that seizures remain uncontrolled amongst almost 50% of people living with epilepsy, which in turn has a huge impact on a patient's life. For example, Moran and colleagues highlighted difficulties in school, unemployment and driving prohibitions as negative consequences of an epileptic seizure. In addition, they emphasised a seizure and its treatment and their joint impact on quality of life. They reported the side-effects from AEDs were associated with no seizure control and, hence poor quality of life could be perceived amongst patients (2004). Previously seizure related accidents and injuries have been documented (Baker, Jacoby, Buck Stalgis, & Monnet, 1997). The patients were asked if they had experienced any seizure related injuries, and it was reported that 27% of patients had experienced head injuries and 13% of them experienced dental injuries. All these experiences were associated with poor perception of quality of life (Baker et al., 1997). More will be discussed about seizure impact and its severity later in this chapter.

The burden of living with epilepsy is not confined to only physical functioning, such as a seizure and its treatment; in actuality, it has broader effects on the quality of life experienced by people living with epilepsy, such as psychological and social impacts (Bishop & Allen, 2003; Kerr, 2012). Given the nature of a seizure is unpredictable; hence the person is unable to control an epileptic seizure. This leads people to experience negative psychological outcomes, such as depression and anxiety, where poor quality of life is perceived as a consequence (Baker, 2002; Kerr, 2012). Psychological well-being of a person with epilepsy has been affected by this

neurological illness, such as low levels of self-esteem were reported amongst those who experienced uncontrolled seizures and, therefore quality of life was perceived as being worse (Baker, 2002; Gauffin et al., 2010).

The impact of epilepsy on an individual's social life is undeniable (McCagh, Fisk, & Baker, 2009). Researchers found that social withdrawal, frustration, emotional problems (Bishop & Allen, 2003); the effects of stigma, family dysfunctions, dependency (Hills, 2007; McCagh et al., 2009), were perceived as negative psychosocial consequences of epilepsy. These psychosocial difficulties have an impact on the perceived quality of life amongst people with epilepsy (Taylor et al., 2011). This is because epilepsy is a long-term illness and social functioning of people may fluctuate (Suurmeijer et al., 2001). In addition, there are legislative restrictions (i.e. inability to hold a driving license), and daily activity limitations which have been documented as negative factors on peoples' lives (Livneh et al., 2001), which all have destructive effects on the quality of life.

Living with epilepsy may cause disruption to an everyday lifestyle and can also affect other aspects of life. For instance it is known that individuals with epilepsy have low rates of employment (De Boer et al., 2008), many lose their job (Kessler, Lane, Shahly, & Stang, 2012), it becomes harder to gain approval for life insurance (Livneh et al., 2001), medication costs and the side-effects of medication (Fisher, 2000), along with the perception of overprotectiveness from family and friends (Livneh et al., 2001; Charyton, Elliott, Lu, & Moore, 2009), these factors all have damaging effects on a patient's life (reviewed in Chapter 1). In addition, the associated uncertainty of a chronic illness over time and fear for the future are the main issues faced by individuals with epilepsy and this can be scary and may lead to the person feeling helpless (Stanton et al., 2007). This uncertainty and worry is high amongst people with epilepsy, as they are not aware when they are having a seizure, and it is common to fall unconscious during a seizure (Kerr, 2012). This could go some way towards explaining why they feel uncomfortable, and avoid being in public. In addition, financial and social ramifications can be seen when an unemployed person with epilepsy has the expense of finding medication costs (Fisher, 2000). This highlights how the social aspects of life can be affected in living with this chronic illness.

All of these aspects, in addition to an underpinning feeling of embarrassment and a feeling of shame for being a person with epilepsy, (as others often misunderstand them and are likely to misjudge them), all affect quality of life.

Taken together, the above studies highlight much more about the perceptions of quality of life in epilepsy; however much less is known about the perceptions of quality of life amongst people living with epilepsy in Iran, as underlined by Zamani and colleagues (2014). Therefore whether the perception of quality of life amongst people living with epilepsy in Iran and the United Kingdom has been influenced by epilepsy has yet to be confirmed.

## **2.5 Other Factors Related to Predict Quality of Life in People with Epilepsy**

There are some additional factors that could influence quality of life, and their effects should also be taken into consideration. This is important for measuring quality of life, and might be relevant and beneficial for individuals with epilepsy both in Iran and the United Kingdom. Although there are many factors which in turn can predict quality of life, those which are relevant to living with chronic illnesses; specifically epilepsy will be discussed in the next section of the literature.

### **2.5.1 Demographic Characteristics**

Age and gender as demographical characteristics appear to be important for chronically ill persons as the illness manifests its difficulty at different ages and in different sex groups (Stanton et al., 2007). Some chronic illnesses are progressive and others may be life-threatening. Therefore the ways in which chronically ill patients perceive their life in different age and sex groups varies (Stanton et al., 2007). As epilepsy can occur in any age group, early onset or late onset, there might be some specific factors that are related to certain age groups, which in turn can affect the quality of life of a person with epilepsy.

Quality of life can be affected by different age ranges in different illnesses. Stanton and colleagues (2007), highlighted as age increases so does the chance of being

diagnosed with at least one chronic illness. For example a decreased quality of life was reported amongst elderly people (Lima et al., 2009). This was a cross-sectional study where it examined the impact of chronic illnesses on HRQOL of elderly people in Brazil. Whilst only 13.6% of people aged over 60 reported not having any chronic conditions, 45.7% reported more than three chronic illnesses. The HRQOL scores were lower in accordance with anxiety, depression, osteoporosis and stroke.

The manifestation of more than three chronic illnesses, (hypertension, back pain, arthritis, arthrosis, depression and anxiety), significantly affected the quality of life in elderly people, especially on the social functioning and emotional role domains (Lima et al., 2009). However another study reported a better quality of life on subjective well-being, (life satisfaction), amongst the older people (Keyes et al., 2002).

With epilepsy, both the age of onset and the duration of epilepsy have played a significant role in peoples' quality of life (Szaflarski, Meckler, Privitera, & Szaflarski, 2006). This research used the QOLIE-89, which may be described as a measure for quality of life which assesses quality of life for patients with epilepsy. Impact of age was examined, as well as age at seizure onset, and epilepsy duration, (time since diagnosis), on the HRQOL amongst individuals with epilepsy. It was found there was a significantly lower quality of life amongst those who were diagnosed with epilepsy at a later age. This was because late seizure onset has more a greater effect due to some practical reasons, such as loss of driving licence and being cautious about having a seizure in public, which may result in a restriction of social life. This could signify a poorer quality of life amongst patients. Whilst the age of onset and epilepsy duration, were highly correlated with quality of life, the age of the patient was insignificant (Szaflarski et al., 2006). This was in contrast with earlier research, which emphasised that a poorer quality of life was perceived amongst those who developed epilepsy at earlier ages (Miller, Palermo, & Grewe, 2003). This was because the study was focused on paediatric epilepsy; whereas, the mean age group was 19 years for Szaflarski et al. (2006) study.

In addition, age at the onset of illness and time since diagnosis and their impact on quality of life have been documented in the other neurological illnesses, such as Multiple sclerosis (MS). It was found that the early age of diagnosis was associated

with better social functioning, both in objective and subjective levels (McCabe & McKern, 2002). This could highlight the importance of measuring quality of life on both objective and subjective aspects.

Previous researchers have shown that gender can predict quality of life (Stanton et al., 2007). The authors stated that women are more likely to feel depressed in comparison to men. In addition women report pain and disability symptoms in adjustment to rheumatoid arthritis illness, more so than men (2007). Women tend to experience lower psychological well-being in comparison to men. This was confirmed by Pud (2011), who examined gender differences and their effects on overall quality of life amongst cancer patients suffering pain. The significant lower quality of life amongst female patients was reported. Pain was negatively correlated with quality of life amongst females; however, this correlation was positive for males (Pud, 2011). This was recognised as standing in contrast with previous research (Casetta et al., 2009), which reported high disability scores on the HRQOL domains amongst MS patients, in comparison to women.

Similarly a study of epilepsy found that females had better scores on physical dimensions compared to males (Rajabi, Dabiran, Hatmi, & Zamani, 2009). These studies indicated gender differences in chronic illnesses, however, a recent study in epilepsy, used the QOLIE-31 questionnaire and reported no significant difference between male and female groups on the perception of quality of life dimensions (Yue, Yu, & Zhao, 2011). The aforementioned studies indicate age and gender differences in several chronic illnesses. Though whether these differences can determine the quality of life for people with epilepsy in Iran and the United Kingdom has yet to be acknowledged.

Various quality of life studies show that urinary incontinence can predict quality of life (Broome, 2003; Ku, Lin, Salmon, & Bron, 2005). They reported high rates of depression and low perceived quality of life amongst people who were suffering from incontinency within the general population. In another study, the more one is incontinent, the poorer quality of life was perceived amongst the elderly (Ku et al., 2005). More evidence for this was provided in the research of Hägglund, Walker-Engström, Larsson, and Leppert (2001), who reported a decreased quality of life in all

dimensions of the SF-36, (a measure to assess quality of life in eight domains), amongst incontinent women.

The abovementioned studies document the impact of urinary incontinence on quality of life in general populations; however, it should be noted that passing urine during an epileptic seizure in epilepsy may differ from being incontinent in other populations. This may be because individuals with epilepsy only pass urine whilst having a seizure. However to the best of the researcher's knowledge, there is insufficient literature to support the view that the psychological impact of this somatic symptom on epilepsy, which has yet to be determined in the current study.

Other factors, such as employment status, socioeconomic status and marital status are reported to affect quality of life not just in epilepsy, but also in other chronic illnesses (Moussavi et al., 2007; De Boer et al., 2008; Heo, Lennie, Okoli, & Moser, 2009; Jacoby, Snape, Lane, & Baker, 2015).

In a study of individuals with epilepsy, unemployment was associated with poorer quality of life (Jacoby et al., 2015). In addition a decreased quality of life was reported amongst those with lower economic status in living with heart failure as a chronic illness (Heo et al., 2009). Further, being divorced or widowed was linked to lower scores in health status amongst depressed people (Moussavi et al., 2007). But it would be difficult to control in all of these factors mentioned, therefore only those factors controlled in this study were reviewed.

## *2.5.2 Physical Variable*

### *2.5.2.1 Seizure Severity*

Seizure severity has been considered one of the key aspects in epilepsy. This is because a seizure is attached phenomenon to epilepsy; therefore its severity should be taken into consideration, which requires measurement with reliable scales (Jacoby, 2000). Quality of life studies in epilepsy show the severity of a seizure can predict quality of life, (Cramer, Baker, & Jacoby, 2002). Evidence for this is provided by a study which reported seizure severity as the main significant predictor for the quality of life in a

population with epilepsy (Harden et al., 2007). They investigated the relationship between seizure severity and quality of life amongst people with intractable epilepsy.

Analysing data from 118 women, it was found that seizure severity was a significant predictor to quality of life and to measure quality of life, the QOLIE-31 scale was applied which covers seven subscales: Overall Quality of Life, Seizure Worry, Emotional Well-Being, Energy/Fatigue, Cognitive, Medication Effects and Social Function. Multivariate linear regression reported Seizure Worry, Social Function, Overall Quality of Life, and Cognitive were inversely correlated with seizure severity. The study suggested that seizure severity triggers the development of anxiety and social isolation, since seizure severity was positively correlated with anxiety, as measured by the seizure worry subscale. The authors highlighted the association of seizure severity with seizure worry and stated that experiencing severe seizures can contribute to worry amongst people with intractable epilepsy. The Social Function subscale refers to social activities which in turn indicate a very important subject such as independence, where a lack of independence can promote anxiety and worry. These psychological factors may impact on the social functioning of people with intractable epilepsy (Harden et al., 2007).

Adebayo, Akinyemi, Ogun, and Ogunniyi (2014), conducted a study examining the relationship between seizure severity and HRQOL amongst Nigerian patients with epilepsy. To measure quality of life, the authors used the QOLIE-31 scale. In order to measure seizure severity, the National Hospital Seizure Severity Scale (NHS3), was used. A significant poorer quality of life was perceived amongst those with high seizure severity. In another study of HRQOL in epilepsy, a poorer quality of life was perceived amongst those with a high severity of seizure (Devinsky et al., 1999).

These studies show that high a seizure severity is associated with poorer perceived quality of life amongst individuals with epilepsy. However whether seizure severity can impact the perception of quality of life for people with epilepsy in Iran and the United Kingdom has yet to be determined.



### *2.5.3 Psychological Variables*

#### *2.5.3.1 Self-esteem*

In 1978 self-esteem was defined by Pearlin and Schooler as, ‘the positiveness of one’s attitude to oneself’ (p.5). It has been found as the main contributory factor to psychological well-being; because the belief and thoughts about ourselves and how to evaluate these beliefs and values in comparison to other people are influenced by the level of self-esteem (Winter, 1996). Earlier self-esteem was introduced by Taylor (1983), in accordance with a response to a threatening event; where there is a human drive to enhance self-esteem after having encountered with such a crisis. This tendency to increase self-esteem was highlighted by Winter, (1996) as a human motive. Self-esteem has an influence on perceived quality of life, of not just the general population but also on the quality of life of chronically ill patients (Jacoby, 2000).

This natural desire to enhance self-esteem is consistent with Wills (1981), theory of downward comparison. In this proposed model, self-esteem can be raised by comparison to someone worse-off; where this type of comparison makes the person feel better, (more detail will be discussed in Chapter 3, Social Comparison Theory).

The uncertainty of an illness can alter one’s level of self-esteem. In addition, reduction in a physical domain may in turn lead to lower levels of self-esteem (Wills, 1981). This was confirmed by a study of breast cancer patients (Bogart & Helgeson, 2000), which reported that decreased levels of self-esteem were associated with uncertainty, which in turn led to negative social comparison.

Existing literature has shown the effect of psychological well-being on quality of life in chronic illnesses, such as epilepsy (Baker, 2002; Suurmeijer et al., 2001). Evidence for this was provided by Collings (1990), who highlighted the association between epilepsy and lowered levels of self-esteem. Those patients seen to have decreased levels of self-esteem showed a poorer perceived quality of life in living with epilepsy. In another study the psychological adjustment of youths with epilepsy was examined, where high seizure frequency was linked to decreased self-esteem (Baker et al., 2005). In addition limitation in social activities and feeling different from others lead people

to experience poor self-esteem (Baker et al., 2005). The abovementioned studies indicate the effect of self-esteem in the perception of quality of life in epilepsy. Still whether this pattern appears in the study of individuals living with epilepsy in Iran and the United Kingdom has yet to be identified.

### *2.5.3.2 Anxiety*

Since anxiety has been clearly defined in the previous chapter, (see section 1.3, Chapter 1); therefore this section will be more focused on the association of anxiety with perceived quality of life in epilepsy. Factors beyond seizure severity have been highlighted as predictors for quality of life. Jacoby (2000), reviewed the literature and emphasised on the role of psychosocial problems, namely anxiety in the outcomes of quality of life for individuals with epilepsy and emphasised that anxiety has ‘a complex relationship with epilepsy’ (Jacoby 2000 p. 114). The unpredictable nature of epilepsy, fear of getting a seizure, risk of physical injuries during an epileptic seizure and even fear of death can all be pivotal in causing individuals to experience anxiety and hence, perceive a lowered quality of life (Kimiskidis & Valeta, 2012).

Anxiety is the most prevalent issue in adults with epilepsy affecting their perceived quality of life (Zeber, Copeland, Amuan, Cramer, & Pugh, 2007). Anxiety and depression have profound effects on perception of quality of life in people with epilepsy. This is confirmed by a study by Johnson, Jones, Seidenberg, and Hermann (2004), which examined the impact of anxiety and depression on the perception of quality of life in epilepsy and accordingly highlighted the negative impact of these elements on perceived quality of life. Although seizure-specific factors, such as seizure frequency and seizure severity affected quality of life, anxiety and depression accounted for more variance than severe and frequent seizures in quality of life for an individual with epilepsy (Johnson et al., 2004). It was concluded that the higher level of anxiety and depression experienced, quality of life was more likely to be perceived poorly amongst patients. The authors further considered anxiety as an additional pressure linked with epilepsy.

In line with this, it was found that anxiety affects quality of life even more than major depressive symptoms. This was confirmed by a study of Kanner, Barry, Gilliam, Hermann, and Meador (2010), amongst people with epilepsy. They compared the impact of anxiety and depression whether there was a difference in the ways in which anxiety and depression can affect the quality of life of people with epilepsy (N = 193). It was reported that whilst 10 people showed depressive symptoms, 21 people reporting anxiety (Kanner et al., 2010).

Although there are few studies looking at epilepsy in the Middle-East, research conducted in Jordan reported high levels of anxiety in adolescents with epilepsy which were associated with lower quality of life scores (Alwash, Hussein, & Matloub, 2000). In addition, an Iranian study highlighted psychological co-occurrence with epilepsy, and examined the contribution of depression and anxiety in the quality of life amongst individuals with epilepsy (Barahmand & Haji, 2014). The QOLIE-31 scale was used to measure the quality of life. A significant negative contribution of anxiety for quality of life was reported. The authors concluded that living with uncertainty in epilepsy may lead patients to perceive worry and a decreased quality of life (2014).

A study on the psychosocial burden of epilepsy (Baker, 2002), found support for the contribution of anxiety with a poorer perception of quality of life, Baker argued that the unpredictable nature of epilepsy was observed as the main factor of psychological difficulties, such as anxiety. In addition, Baker reviewed the impact of epilepsy in developed and developing countries and stated that there is well published literature for the psychosocial consequences of epilepsy in developed countries. However due to insufficient resources to conduct research, little is known about the psychosocial impact on people with epilepsy in developing countries (2002).

Taken together, the above studies emphasised that demographic characteristics, the physical domain (seizure severity), and the psychological domains (self-esteem and anxiety), are associated with the perception of quality of life in epilepsy. However whether these patterns emerge in the study of individuals living with epilepsy in Iran and the United Kingdom has yet to be confirmed.

## 2.6 Quality of Life and Adjustment

The above sections illustrate how epilepsy as a chronic illness affects the perception of quality of life. However looking at the importance of subjective aspects in the perception of quality of life, it becomes evident that the impact of illness is not permanent (Dibb & Yardley, 2006). Although individuals may perceive illness as the most distressing factor in their life when they have just been diagnosed with illness, this feeling will subside over time. They will achieve life satisfaction, because the subjective quality of life may perceive a better understanding of life. This indicates that individuals are more likely to recover from threatening events from a cognitive point of view (Taylor, 1983). When persons are encountered with crisis, they try to re-evaluate themselves to see what has been changed so far; in a way they try to adapt themselves to the new circumstances. This alteration in the perception of quality of life leads to adjustment. Therefore it should be acknowledged that adjustment may be linked with quality of life; this is because adjustment offers ways in which people can adapt themselves to the altered situation and potentially perceive a better understanding of their life as a consequence (Dibb & Yardley, 2006).

Epilepsy as a chronic illness has some psychological and psychosocial burdens, Suurmeijer and colleagues (2001), in their study of people with epilepsy found adjustment and coping as one of the factors that contributes to patients' quality of life. Earlier, Taylor (1983), found patients with breast cancer had a positive evaluation of their circumstances, showing positive adjustment to their illness. Patients considered themselves as better adjusted prior to their treatment, while they were asked about what changes had happened to them. In addition, Taylor (1983), proposed the Cognitive Adaptation Theory as a model of adjustment in quality of life. The model states that when people are faced with threatening events, they react to the threat cognitively in order to retain their psychological functioning. In particular, the author emphasised self-enhancement to improve self-esteem as an adjustment process to chronic illness. This happens through comparison to someone worse-off. She considered downward comparison as a way of increasing self-esteem, and having better adjustment as a consequence, (more will be discussed in Chapter 3).

Since the importance of adjustment in perception of quality of life has been reviewed, it is worthwhile to review briefly, literature on coping and psychosocial adaptation to epilepsy and their impacts on the perception of quality of life in the following section.

## 2.7 Coping

An effective coping strategy is important to achieve psychological well-being, especially in uncertain stressful circumstances (Carver, Scheier, & Weintraub, 1989). Coping processes involve two main functions: 1) problem-focused coping and 2) emotion-focused coping. Problem-focused coping involves the active management of the problem that is causing stress to the individual, for instance, planning a solution to the problem. Emotion-focused coping on the other hand, acts to regulate emotions associated with stressful events, such as emotional expressions, (Folkman & Lazarus 1980). Emotional expression as a coping strategy usually refers to a strategy where a person is eager to express one's emotion, for instance with anger or weeping whilst in the others presence, (Livneh et al., 2001). Researchers suggest there are various coping strategies that may fall into any of the two main coping styles. Information seeking for instance, which is conceptualized as an active task-oriented strategy, in turn refers to a problem-focused coping strategy, (Livneh et al., 2001). Emotional expression, venting and emotional support are positioned as coping strategies where a person releases their emotions with crying or anger to regulate their emotion, which are examples of emotion-focused coping strategies (Livneh et al., 2001). Researchers further argued that there are some other types of coping strategies which have been considered as maladaptive in accordance to the type of stressors, namely emotion-focused coping which covers avoidance, denial, distancing and wishful thinking which may in turn have destructive effects on the adaptation process to stressful events, (Livneh et al., 2001; Goldstein, Holland, Soteriou, & Mellers, 2005). Earlier, Lazarus and Folkman (1987), highlighted depression and anxiety as consequences of emotion-focused coping strategies, as this type of coping can proceed to a person having maladaptive coping in the long-term adjustment.

It is known that emotional expression in the short-term, appeared to be an effective coping strategy; however if it takes longer than expected it will become maladaptive, and destructive (Livneh et al., 2001).

In addition coping researchers have also emphasised on the importance of religion and spirituality as an effective coping strategy (Craver et al., 1989). Literature suggests that religion and spirituality is constructive in people dealing with life-threatening illnesses and people with emotional problems (Craver et al., 1989). The abovementioned studies explain the various types of coping strategies. Still whether this type of coping emerges amongst people with epilepsy in Iran and the United Kingdom has yet to be determined.

### *2.7.1 Coping and Psychosocial Adaptation to Epilepsy*

Individuals' physical, psychological and social functions have been affected by the ways in which they cope with their stress (Folkman & Lazarus, 1980). Due to the sustained nature of chronic illnesses and its impact on quality of life, it is essential to recognize ways in which individuals deal with their illness, and how the illness can be managed (Westerhuis, Zijlmans, Fischer, Van Ande, & Leijten, 2011). Since coping is seen as an individual's response to a threatening event (Folkman & Lazarus, 1988), it is worthwhile exploring coping strategies used by individuals with epilepsy to manage demanding circumstances. This is because effective coping strategies have substantial influences not just on physical health but also on social functioning, and the psychosocial adjustment of people living with epilepsy (Krakow, Buhler, & Haltenhof, 1999). Epilepsy is one of the challenging and demanding neurological conditions which once diagnosed, is a condition they have to live with for life (Cramer et al., 1998; Jacoby, 2000). It is known that epilepsy as a chronic illness involves uncontrolled and unpredictable seizures (Baker, 2002). Previous research found that patients with epilepsy perceive their life as more threatening and stressful in comparison to the general population (Oosterhuis, 1999). The author argued that medication treatment and psychological distress associated with epilepsy have destructive effects on the perceived quality of life. Recently, Westerhuis et al. (2011),

examined different coping strategies and their effects on the quality of life for patients diagnosed with partial epilepsy. They reported more avoiding coping strategy, specifically amongst women who showed less active coping styles which in turn were associated with a lowered perceived quality of life.

The effects of coping strategies on the psychological well-being of people living with epilepsy have been well documented (Goldstein et al., 2005). Evidence for this is provided by research conducted in the United Kingdom amongst people with epilepsy (Krakow et al., 1999). They examined the coping strategies amongst 40 patients and their association with psychosocial adaptation to epilepsy. They reported problem-focused coping as an active coping strategies which were frequently used by the patients. Krakow et al. (1999), highlighted problem-focused coping strategies as being effective and constructive in terms of increasing psychological well-being. This was in line with another study of adaptation to epilepsy (Livneh et al., 2001); suggesting that the more problem-focused strategies were applied, the better psychological outcomes, such as higher levels of illness acceptance, and lower anxiety were perceived; this is because people actively managed their illness to solve the problem.

Emotion-focused coping strategies have also been used in the study of adaptation to epilepsy (Oosterhuis, 1999). Evidence for this is provided by an Iranian study which reported an emotion-focused strategy as a coping style amongst people with epilepsy (Hosseini et al., 2010). They carried out a qualitative study with 21 patients in Iran and reported that Iranian people tended to use emotion-focused rather than problem-focused strategies, which in turn helped them to overcome their medical condition. In line with this, Rätty, Söderfeldt, and Larsson (2007), argued that emotion indeed is a part of the coping process which reflects an individual's emotional experiences. They further stated that emotion is a particular reaction to a threatening event which may in turn be regarded as an individual's effort to survive (2007). This was confirmed recently by Bautista, Rundle-Gonzalez, Awad, and Erwin (2013), who showed epilepsy patients, were more likely to seek support from others, and found this as actively managing their condition.

The positive effect of religious coping has also been documented in an Iranian study amongst epilepsy patients (Hosseini et al., 2010); signifying the positive impact of this

type of coping as it empowered individuals and assisted them to overcome their problems. Hosseini et al. (2010), further considered religious belief as an active coping mechanism, as it helped patients and enabled them to accept their illness. Another study of Chilean women with breast cancer (Choumanova, Wanat, Barrett, & Koopman, 2006), showed that religious beliefs have a significant role in the adjustment process to chronic illness. It was a qualitative study, and 27 women were interviewed in this research. The authors argued that religious beliefs provided the patients with better mental and physical health. Another study highlighted religious/spiritual coping as a positive coping strategy amongst cancer patients (Thune-Boyle, Stygall, Keshtgar, & Newman, 2006). It was suggested that this type of coping has multiple functions in the long-lasting adaptation to cancer such as increased self-esteem, improved emotional well-being and being hopeful about the future. In addition recent Brazilian research showed that religious/spiritual coping strategies have significant roles as positive coping techniques for patients with temporal lobe epilepsy (Tedrus, Fonseca, Magri, & Mendes, 2013).

Coping with epilepsy is not only confined to general coping strategies. Further evidence suggests advanced techniques may help people manage their illness. Assistant dogs or seizure alert dogs for example, could be helpful in terms of managing epilepsy as a chronic illness. The benefits of service dogs have been well-documented in disabilities (Crowe et al., 2014), and mobility challenges (Fairman & Huebner, 2001). The benefits of service dogs have also been highlighted in a study of Dalziel, Uthman, Mcgorray, and Reep (2003), indicating that people with other neurological conditions, such as Parkinson's disease and Alzheimer's disease have received support from these service dogs. This indicates trained dogs can assist individuals with disabilities to perform everyday tasks. These dogs are allowed in all public areas to accompany a disabled person. Researchers have provided evidence for existing seizure-alert dogs where they can intuitively show attention-getting behavior before the seizure onset in epilepsy, (Strong, Brown, Huyton, & Coyle, 2002; Dalziel et al., 2003). It was shown that these dogs are more likely to stay with the person who developed a seizure, until the seizure subsides (Strong et al., 2002).



## 2.8 Conclusion

The definitions of quality of life have been reviewed in this chapter. The conceptualization for quality of life in this study is based on the HRQOL models, namely A Patient-Based Health-Related Quality of Life Model in Epilepsy, and the Biopsychosocial Model. Perceived quality of life is shown as a functional element since it has focused on the impact of illness on health and on a daily basis. Epilepsy and how it affects the overall quality of life has been highlighted. Significant factors that could potentially predict quality of life in epilepsy also has been discussed.

Quality of life is a multidimensional construct, and the importance of measuring this concept from different perspectives in order to have a comprehensive view of quality of life has been reviewed. The interpretations taken from the review of the literature resulted in the functioning definition of quality of life, which was derived from the HRQOL model that defined in epilepsy. Quality of life, it suggests, results from a subjective perception for the impact of an illness on individuals which covers not only health but the physical, psychological and social functioning of a person. A second definition can be derived from the Biomedical model; looking at the illness itself (from a biological perspective), however is not enough in order to determine quality of life as there are additional factors beyond the physical aspect that could have an effect on the perception of quality of life, such as psychological and social elements. Hence, the Biopsychosocial model is believed to present a more holistic approach to the understanding of quality of life in chronic illness, specifically epilepsy.

Although the main aim of the current study is centred on establishing the role of social comparison on predicting quality of life for people with epilepsy, the conclusion drawn from the review of literature highlighted the importance of measuring demographic characteristics, physical variable and psychological domains and their impact on the perception of quality of life. Therefore it is necessary to measure these variables before determining the true effects of social comparison dimensions. In order to be successful in this, all of the abovementioned domains will be controlled, in an effort to see whether social comparison dimensions could predict the quality of life for people with epilepsy in Iran and the United Kingdom.

This chapter outlined the definition and measurement for quality of life which will be measured as the outcome variable in this thesis. The next chapter will be focused on a review of the Social Comparison Theory, providing an explanation of the main predictor variable of interest.

## **CHAPTER 3: THEORY OF SOCIAL COMPARISON**

### **3.1 Introduction**

The main question of this research is ‘what is the role of the social comparison process on the perception of quality of life amongst people living with epilepsy in Iran and the United Kingdom?’ Following the previous chapter which focused on quality of life this chapter aims to follow with detailed explanations of the Social Comparison Theory. In order to do this, this chapter defines what social comparison is and what the theories behind this process are. It will follow the chronological order of the evolution of social comparison (Buunk & Gibbons, 2007). It then will be followed with a justification of why this theory is appropriate to discuss with chronic illnesses and in particular, epilepsy.

Previously it has been established that the social comparison process can in fact be effective in perceiving quality of life (Dibb & Yardley, 2006), other individuals’ opinions and abilities could determine how our own abilities and opinions fit in comparison to them (Festinger, 1954). This type of comparison will help individuals not only to judge their own opinion and abilities, but also control their own emotional reactions (Buunk & Gibbons, 2007), and self-esteem (Wills, 1981). Since it has been previously shown that social comparison can be influential in the perception of quality of life, the main implication of this study will be focused on the role of social comparison on the perceived quality of life amongst people living with epilepsy.

### **3.2 The Theory of Social Comparison**

The Social Comparison Theory originally was authored by Leon Festinger in 1954. It has been considered as one of the leading approaches to explain the way people compare themselves to others and was the first development in the social comparison process. The theory mainly focuses on the social comparison process in individuals and related groups. It proposes that individuals have a desire to self-evaluate, as this self-evaluation can help them to identify what kind of behaviour is suitable for them (Festinger, 1954). In addition, Festinger proposes that, when individuals are uncertain about their opinions or abilities, in order to assess their own conditions they will

compare themselves with others (1954). For instance, to evaluate your skill in a particular game, you could compare yourself with various objectives or social standards (Festinger, 1954). In general social comparison is a process of comparing oneself with other people, where other people are termed as the 'target' group (Buunk & Gibbons, 2007).

Festinger's principal idea was that a human has a 'drive to evaluate his opinions and his abilities' (1954, p.117). Individuals employ social comparison for two purposes: 1) *self-evaluation*: defining their own position in comparison to others; 2) *self-enhancement*, which is the achievement of a constructive evaluation of the self (Festinger, 1954). This theory details that, usually, an individual's preference is to evaluate themselves with objective standards; however in the absence of such objective information, they are more likely to compare themselves to other people; as they need to determine where they stand in comparison to others (Taylor & Lobel, 1989). This is what happens in the case of chronic illness since the objective standard of well-being disappears (Bogart & Helgeson, 2000), and individuals start to compare themselves with other people for the purpose of evaluation.

Research has shown that different types of social comparison are used. Finlay and Lyons (2000) distinguished amongst three types of comparisons, namely *Upward*, *Downward* and *Lateral* social comparison dimensions. Upward comparison is when the other person or persons are presented as being in a more favourable position (comparison with someone better-off). Downward comparison is when the self is presented as occupying a more favourable position, (comparison with someone worse-off), and Lateral comparison is where the self is presented as the same as another person on some attribute, (comparison with similar others).

The dimension of the comparison is important. For instance how the experience of living with epilepsy may be associated with their comparison dimensions. Losing a driving license, for instance, not being able to drink alcoholic beverages, and loss of autonomy and independence, all in turn, may lead individuals to feel dejected. They may engage in upward contrast, where they feel they are not as fortunate as other people who drive, drink, and have their own independent life, (more detail will be discussed in Chapter 5). With this type of comparison, individuals perceive a threat

and accordingly begin to increase the distance between their own positions in life and with other people (target group). This is where envy can happen based on the negative feelings experienced (White et al., 2006). In addition, Arigo and colleagues (2014), in their review expand on this, and further stated that contrasting with a greater target may remind individuals about their own standing position in life which could lead them to feel depressed, frustrated and inadequate. Buunk, Zurriaga, and González (2006), support the negative effect of upward contrast amongst people with a spinal cord injury, and stated that the more an individual feels frustrated and powerless in comparison to a target perceived as being better-off, the more the individual is likely to feel depressed.

It is possible that individuals think about some potential factors that could lead them to feel in a similar way to a threatening target. In this case, dissimilarities can be seen as the dimension which can help to reduce the perception of feeling similar to that particular target. As an example, passing urine during an epileptic seizure would be an unpleasant experience of living with epilepsy. The incontinent person might prefer to seek dissimilarities in other dimensions, such as a comparison to elderly people, who may have a leakage problem most of the time or people with urine trace infections; or with individuals suffering from a bladder infection. This feeling of being dissimilar diminishes the negative similarity on urinary incontinence dimensions. This is because in their case, they only pass urine during a seizure and this would not persist for more than a few seconds, (more about this will be discussed in Chapter 6). This was confirmed by an earlier study of Gibbons (1999), who reported fewer physical issues amongst students when they were interviewed by a disabled person. This is because the students had difficulties in their academic field; nonetheless, when they met the disabled person, they noticed that their situation was not bad as the disabled target. However this report showed dissimilar findings for those students who were interviewed by a healthy person. This highlights social comparison's influence on how students refuted their own problem as they interacted with a disabled person whose situation was worse than their own.

This type of exposure then led them to feel better about themselves in comparison to the target (Gibbons, 1999). This may help individuals to 'count their blessings,' that their circumstance was better in comparison to the target. Similarly this could be

applied to a person with epilepsy who passes urine during an epileptic seizure. In some regard, they may feel better or feel lucky that at least, they only pass urine during a seizure and not for an entire day as their target.

A second key development in the Social Comparison Theory was grounded in alternative explanations for this theory, namely the fear/affiliation theory by Schachter (1959). The concept of threat in social comparison was underlined by this author. Schachter showed stress and affiliation in his experiment amongst female students. Those who were in fear of an electric shock preferred to wait with those who were waiting for the same event rather than with others (1959). In addition, Schachter positioned that if individuals felt threatened, they engaged in comparison with those either in the same situation, or those in better circumstances. These findings led him to establish the threat/affiliation theory. Later another review study highlighted an affiliative need amongst those who feel uncertain. Buunk and Gibbons (2007), underlined this affiliation and stated that, when individuals feel uncertain about the particular threat, they tend to affiliate with others to reduce their stress and manage their emotions. Therefore social comparison can occur amongst people living with chronic illness as diagnosis of an illness can be considered a threat, causing the person to feel uncertain about that particular threat (Dibb & Yardley, 2006).

The need for comparison was evident by a study of Bennenbroek and colleagues (2002), amongst cancer patients, social comparison was the highest point amongst those who evaluated their health negatively. In particular, patients were engaged in comparison with fortunate others, as they were uncertain and needed to gather information. The more the feelings of uncertainty, the more the need for social comparison were experienced. In addition, Bennenbroek et al. (2002), reported social comparison as a way of achieving information for cancer patients, which helped them in the coping dimension. The more information obtained either from fortunate others or from similar targets, the greater the level of coping observed. This was confirmed earlier by Helgeson and Mickelson (1995), who stated that feeling similar to others leads the person to feel relieved that they are not the only one who has that particular problem. In line with this, Van der Zee, Buunk, and Sanderman (1998), previously found evidence amongst patients with breast cancer and reported that patients preferred to get more information from those who were in a better situation, rather

than those with worse-off conditions. This makes social comparison more likely to be a process amongst people living with epilepsy. This is because seeking information from fortunate others may help them to be inspired and feel hopeful about themselves, (discussed in Chapter 1). However, this is a new approach to see whether social comparison does occur amongst people with epilepsy.

The theory of downward comparison was the third development in the evolution of the Social Comparison Theory (Buunk & Gibbons, 2007). This was introduced by Wills (1981). He proposed that when individuals encounter a threatening experience, they prefer to compare themselves with others who are less fortunate. When a person's subjective well-being decreases because of unfortunate circumstances, the solution is a favourable comparison with less fortunate others which will enable individuals to feel positive about their own position. The principle of this theory is that individuals can enhance their own subjective well-being by comparing themselves with others worse-off and therefore reduce their negative feelings; where this type of comparison leads them to have an enhanced subjective well-being (Wills, 1981).

Wills (1981) underlined the association of the downward comparison with self-esteem and stated that individuals with low self-esteem are more likely to engage in downward comparison. The basis of this type of comparison is grounded in an inspiration to achieve an enhancement of their subjective well-being. Therefore, individuals with low self-esteem are more likely to be motivated by self-enhancement. The downward comparison helps ego enhancement (Stanton et al., 1999). This also has implications for people with epilepsy, where downward comparison and its positive effects amongst incontinent people may be noticeable; as they may feel better in comparison to others who are leaking all of the time (reviewed in Chapter 1). This is because they may realise that they are not as bad as the target. This type of comparison may increase their self-esteem. This is in line with a study by Bogart and Helgeson (2000), highlighting downward comparison as the most common type of comparison amongst breast cancer patients.

They found that downward comparison was associated with positive effects (Bogart & Helgeson, 2000). They further stated that the patients' primary focus was on self-enhancement. This was achieved through comparison with a worse-off target. An

earlier study of cancer patients (Wood, Taylor, & Lichtman, 1985), found that patients made downward comparison with unfortunate others in order to boost their self-esteem. They also argued that as the threat increases, downward comparison was more likely to occur. Similarly, Dibb and Yardley (2006), found support for downward comparison in their study with Meniere's disease, where better health status was linked to positive effects of downward comparison.

A fourth main development in the evolution of the Social Comparison Theory was the introduction of a social cognition approach in the Social Comparison Theory (Buunk & Gibbons, 2007). In 1985, Wood and colleagues took a step further and purposed social comparison as social cognition. They stated the social comparison process is just a process; rather it is a cognitive process in which a person tries to decrease a threat when they encounter a threatening situation. This is however inconsistent with what Festinger (1954), originally called the social comparison 'process'. Wood and colleagues expanded on the cognitive nature of social comparison and stated that thoughts of individuals can range from imagining the threat as being as bad as possible, to having a positive standpoint about that threat (putting the threat in a good perspective, such as considering the other successes that they may have, instead of thinking about negative point of that threat). They termed these responses to the threat as 'cognitive' rather than a process in social comparison, as no comparison takes place (1985). Similar to Festinger, they believed that social comparison had two main functions: 1) it can help with self-evaluation and 2) for self-enhancement, since they believed comparison can in fact lead individuals to perceive positive experiences that will help to have high self-esteem (Wood et al., 1985). The cognitive process of social comparison then took on an informational perspective. Buunk and Gibbons (2007), expanded on this in their review stating, that in order for an individual to recognise their own self-perception in the comparison of social consequences they need to evaluate their knowledge during the comparison of others, in order to see how they can judge themselves through this knowledge.

In 1989 Taylor and Lobel, proposed that upward and downward comparisons may have different reasons to occur in individuals. It is possible that one person can engage in either upward or downward comparisons; however, this would depend on their circumstances. They stated that while achieving information and having social



contacts, resulting from upward comparison, self-enhancement could happen as a result of downward comparison.

They expanded on this and stated that in upward comparison, fortunate targets have the required information to provide the comparers with noticeable knowledge. However worse-off targets are not as qualified as fortunate others to give information, yet they could lead the comparer to perceive positive effects, such as feeling satisfied that they are doing okay. Taylor and Lobel (1989), argued that downward evaluation should lead an individual to feel reassured about his/her superior standing. They stated that upward contacts and downward evaluation can occur concurrently under the same psychological conditions. They underlined social comparison as a process in which there is a desire to affiliate with fortunate others and the tendency to achieve information about others (Taylor & Lobel, 1989).

An earlier study of cancer patients (Taylor & Dakof, 1988) supported this and reported that acting as a 'good role model,' is the most helpful action for patients, helping them to survive and adjust well. Similar studies for cancer patients (Stanton et al., 1999; Bennenbroek et al., 2002), support the upward affiliative comparison and reported a greater desire in patients for affiliation and emotional support from the well-adjusted patients, than with worse-off individuals.

In another study of cancer patients, Bogart and Helgeson (2000), highlighted upward comparison as the information resource for patients and in contrast they reported self-enhancement as a result of the downward comparison. Festinger (1954), supported the idea of upward comparison and stated that there is an 'unidirectional drive,' amongst people who attempt to be better their current level of performance. To do this, he contended that individuals strive to be seen as more capable than both their current performance and more talented than the comparison target (Taylor & Lobel, 1989).

However, this is in conflict with Wills (1981), argument which indicated that ego enhancing is achievable by downward comparison with less fortunate others. Taken together, achieving upward information and searching for affiliation is served for self-improvement (Stanton et al., 1999). This also has implications for individuals with epilepsy, where upward contacts and affiliation and its potential positive influences in

their life may be noticeable, as this type of comparison may induce hope and inspiration for individuals with epilepsy.

The social comparison domains have been continuously expanding, with more important factors being explored from a theory of comparison perspective. In this regard, social comparison was taken a step further and developed by Buunk, Collins, Taylor, VanYperen, and Dakof (1990). These authors proposed that upward and downward comparisons have more detailed explanations to those previously explained. They emphasised on the 'interpretation,' of upward and downward comparison, rather than simply a direction. Buunk et al. (1990), believed that both types of comparisons could be interpreted in a positive and a negative way. Downward comparison can be interpreted in a positive way, where the individual perceives a better feeling after comparison with an unfortunate target, (i.e. feeling of being fortunate as his/her situation is not as bad as that target).

The opposite of this can also occur where the comparison is interpreted in a negative way. This happens when a person starts to perceive a negative feeling after comparison with a worse-off target; instead of feeling fortunate, the person feels apprehensive, and may become nervous as he/she is worried about finding themselves in a similar or the same situation as the target one day in the future. On the other hand, upward comparison can be interpreted in a positive way, where the person feels inspired and is hopeful in comparison to the fortunate target (i.e. feeling positive, it is possible to be like this person in the future, I can also do it).

Alternatively negative feelings could be perceived when the person compares themselves to a better-off target and feels negative as he/she could never be like the target. In such circumstances, the person feels dejected, and feelings of jealousy could result (Buunk et al., 1990). Buunk and colleagues reported positive upward comparison as the most frequent type of comparison that had positive affects amongst cancer patients.

The importance of 'interpretation,' of comparison dimensions encouraged Buunk and Ybema to develop the Identification/Contrast model of social comparison (1997). This model proposes that the interpretation of social comparison information is dependent upon whether people contrasted or identified with comparison targets. They explained this fact with reference to this example if we compare ourselves to

someone who is better off than ourselves, we are comparing with an ‘upward’ target. In this type of comparison, if we feel that we could be similar to that person, then it can be said that we have identified with the target and as a result, we will experience a positive affect (positive upward comparison). This is because there was a focus on the positive aspects of the fortunate target, which gives hope and inspiration as there is the potential to be like that target. Conversely, if we believe that we can never be as well-off as the target, in this case, we have contrasted with the target which leads to the experience of negative effects (negative upward comparison). This is due to the perception of a threat. The opposite of this model was adopted by these authors as well. In a comparison with someone worse-off than ourselves, (in the case of feeling fortunate that our situation is not as terrible as that of the target), then it can be said that we have contrasted, (positive downward comparison). However if we feel frightened that we might be in that situation one day, then we have identified with the target and as a result, we will experience a negative effect; because we only focus on similarities between ourselves and the unfortunate target. This type of comparison refers to the negative downward comparison, taken together with the Identification/Contrast model recognised upward identification and downward contrast as the healthier type of social comparison (Buunk & Ybema, 1997). These two types of comparison are termed as ‘positive-outcome comparisons,’ as they lead a person to have desirable self-judgments and perceived positive effects as consequences, (Arigo et al., 2014). Arigo and colleagues (2014), however conceptualised the upward contrast and downward identification as a ‘negative-outcome comparison’. This is because they induced negative feelings and undesirable judgment.

On this point, consistent with the literature, the mechanism of social comparison has been drawn upon, the three types of social comparison dimensions were highlighted and the interpretations of upward and downward comparison were illustrated. It is worth noting that whilst evidence for the social comparison process in people with epilepsy has not been investigated yet, there is well documented evidence suggesting the dimensions of social comparison in other chronic illnesses. Therefore the next section will be focused on the role of social comparison in several chronic illnesses, and how it effects the perception of chronically ill people.

### 3.3 The Role of Social comparison in Chronic Illness

Implications for the social comparison process in people living with chronic illnesses have been well established in many studies. In general there are many reasons to justify why people with chronic illnesses use social comparison strategies. Dibb and Yardley (2006), highlighted the nature of the illness and living with a long-lasting illness as relative factors that might lead individuals to do comparison spontaneously. In addition a feeling of uncertainty and lack of objective information in chronic illness makes comparison more likely to happen (Arigo et al., 2014). Arigo and colleagues systematically reviewed the social comparison literature and discovered the length of time from diagnosis of an illness may lead individuals, to do a comparison in order to judge a new lifestyle. In addition perceiving the illness as a threat may lead patients to do comparison in the hope of feeling better and enhancing their well-being (Tennen, McKee, & Alffleck, 2000; Bogart & Helgeson, 2000; Dibb & Yardley, 2006).

Some chronic illnesses involve a ‘vague prognoses,’ in which a person may experience a constant threat to their self-concept which could result in uncertainty about their future. The feeling of uncertainty can result in social comparison to diminish ambiguity and repair a sense of self (Arigo et al., 2014). This could be applied to people living with epilepsy, as the nature of the illness is unpredictable. Therefore diagnosis with epilepsy and experiencing seizures could lead individuals to feel ambiguous and uncertain about the future of their health standing, which results in a perceived threat to the person’s self-construction. Perhaps a social comparison is more likely to happen as a consequence of uncertainty in living with epilepsy.

It is evident that the interpretations of social comparison dimensions have different implications in different domains. Buunk et al. (1990), investigated different types of social comparison, dimensions between two groups of people: women with cancer, and couples with marital dissatisfaction. Both study groups revealed that social comparison dimensions are not ‘intrinsically’ associated with effective outcomes; however, individuals can experience either negative or positive effects from comparison. This flexibility depends on individuals whether they have contrasted or

identified with the target. Buunk and colleagues (1990), found that positive upward comparison in the first study group with cancer patients produced positive consequences; yet the same dimension did not have positive effects for the married couples. They concluded that in living with a chronic illness, such as cancer, seeing positive examples of how well other patients are doing might be encouraging and inspiring patients (upward comparison), as they feel similar to the target and feel they too could be like the target group. Whereas in the condition of normal life (without illness), upward comparison in marital relationships could be embarrassing where if couples inform other people of how badly they are doing, it is as if they are 'announcing' how bad their relationship is. In addition Buunk and colleagues indicated the social comparison process can influence an individual's self-esteem. This was because they reported positive downward comparison generated positive effects amongst those with lower self-esteem (1990). This study was consistent with research from Taylor and Lobel (1989), on the social comparison dimensions amongst cancer patients which revealed upward contacts, receiving information from people who were in a better situation amongst patients and being exposed to the better off comparison target, resulted in emotional functions, such as inspiration and optimism. Other research highlighted the importance of upward comparison to self-enhancement, (Blanton, Buunk, Gibbons, & Kuyper, 1999). However, Bogart and Helgeson (2000) reported downward comparison dimensions as the most common types of comparison amongst women with breast cancer, where patients felt well by comparison with others who were worse-off.

The authors reported that upward comparison dimensions were more likely to be associated with negative effects as patients felt frustrated by an inferior condition. Downward social comparisons and their positive effects were also reported in other chronic illnesses (Gibbons & Gerrard, 1991; Dibb & Yardley, 2006).

More evidence of social comparison dimensions was found in the study by Dibb and Yardley (2006), where the patients with Meniere's disease made a wide range of social comparison dimensions. These include upward comparison, downward comparison and lateral comparison. This was a longitudinal study where they examined the effect of social comparison on people living with Meniere's disease on coping dimensions. The main results revealed the effects of social comparison interpretations on the

perception of quality of life amongst these patients. It indicated the difficulty of interpretation due to the progressive nature of the illness which was associated with a tendency to interpret a downward comparison negatively. The authors stated that a better health status was associated with more positive downward and upward comparisons. They also emphasised that in a real life context, people generally are eager to select the comparison dimension which enables them to perceive positive effects. Dibb and Yardley (2006), concluded that the lateral comparisons with similar others, were more common in real life contexts. Similarly, Bellizzi, Blank, and Oakes (2006), found support for lateral comparison in their qualitative study of cancer survivors. The results were analysed using thematic analysis, and it was reported that in contrast with previous research where comparison directions were applied, the lateral comparison was the most common type of comparison amongst these people. The aforementioned studies reveal social comparison is linked to the way in which quality of life is perceived.

In an experimental study of cancer survivors, Brakel, Dijkstra, Buunk, and Siero (2012), examined the effects of information from social comparison and impact on the perceived quality of life. Patients were randomly assigned to either one control condition or one of three experimental conditions where they were interviewed with peer cancer patients. After 2 months, the individual's quality of life was assessed. The impacts of the interviews were dependent on the patient's health status reports.

Patients with felt their well-being was good, were more likely to receive information from their fellow cancer survivors. This study highlighted how the interviews affected the intervention on perceived quality of life after 2 months. In this study, those patients with high scores for health status, perceived social comparison information positively. This in turn led them to have a better perception of quality of life. This was in contrast with those patients who perceived a poorer quality of life, as they perceived social comparison information negatively.

The psychological influences of social comparison processes should not be underestimated. A cross-sectional study of social comparison emphasised on this and highlighted the psychological effects of social comparison amongst cancer patients. They reported more feelings of depression, anxiety, uncertainty and lack of control

over their illness, the more social comparison that is required to see how well the patients are doing in comparison to others will help them to attain information about their own health status (Bennenbroek et al., 2002).

Similarly, Gibbon, Blanton, Gerrard, Buunk, and Eggleston (2000), established upward comparison as an inspiration and a way of bringing hope to people. Gibbons and colleagues' study was a longitudinal one, where the effects of social comparison on students' performance were noticeable. However the negative psychological consequences of social comparison were also documented (Wilson, Gil, & Raezer, 1997).

Evidence for this is provided by Heidrich and Ryff (1993) earlier study. Their cross-sectional survey reported elderly people who had experienced problems in their daily activities had less psychological well-being when they were engaged in social comparison. Whilst those engaged in positive downward comparison reported less psychological distress, high levels of depression were reported amongst those who engaged in negative social comparison. They found an association of social comparison and psychological health issues; yet it should be noted that since the study of Heidrich and Ryff (1993) and Bennenbroek et al. (2002), were cross-sectional, the causal relationship of the variables could not be established. In addition the effects of social comparison on psychological and physical well-being in living with chronic illnesses have also been reviewed in Arigo et al. (2014).

Bogart and Helgeson (2000), supported the link between social comparison and psychological effects. This was a naturalistic evaluation of social comparison where comparisons were occurring in daily life. An increased self-esteem amongst those who engaged in downward comparison was reported amongst their cancer patients. They had a better perception of their illness (Bogart & Helgeson, 2000), this result was earlier confirmed by Wills (1981), who suggested that a person with low self-esteem should make more downward comparison than the other comparison dimensions, as he/she requires self-enhancement. A study of social comparison interpretation amongst individuals with Meniere's disease supports the psychological effect of social comparison and stated that those with high levels of self-esteem, and

optimism, perceived control over their illness and were engaged in positive social comparison, leading to a perception of a better quality of life (Dibb & Yardley, 2006).

The abovementioned studies highlight social comparison influences on the perception of quality of life in different chronic illnesses. However there is insufficient literature to show how social comparison, as a mechanism, can affect the perception of quality of life amongst people living with epilepsy. This leads to the investigation of social comparison and whether it can impact the ways in which quality of life has been perceived amongst individuals living with epilepsy as a chronic illness. Therefore it is worthwhile examining this theory in order to have a better understanding of perceived quality of life amongst the epilepsy population. Whilst filling this gap, this thesis will contribute to the growing body of knowledge that the Social Comparison Theory can in fact be effective in terms of perceiving quality of life in living with epilepsy. As an example, passing urine during an epileptic seizure may encourage individuals to engage in positive downward comparison, and as a result, they may have a better perception of their health. This can lead individuals to consider social comparison as an adjustment process to epilepsy. That is if it helps in the adjustment to urinary incontinence.

Since there is a lack of literature showing the role of social comparison as an adaptation process in epilepsy; therefore it is essential to understand this mechanism in other chronic illnesses. The next section will focus on the mechanism of social comparison as a coping strategy amongst different types of chronic illnesses to see how social comparison is practically implemented in adjustment amongst chronically ill people.

### **3.4 Social Comparison and Adjustment to Chronic Illness**

Previous research has shown that in individuals with chronic illnesses, social comparison dimensions are implemented as adjustment strategies to the chronic conditions (Buunk et al., 1990; Bogart & Helgeson, 2000; Van der Zee, Buunk, Sanderman, Botke, & Van Den Bergh, 2000; Dibb & Yardley, 2006). Evidence for this is provided by Van der Zee and colleagues (2000), who demonstrated the impact of social comparison on the adjustment process. They developed the



Identification/Contrast scale for social comparison (I/C), which is based on interpretation of the four social comparison dimensions. They have termed 'positive interpretation of social comparison,' which covers upward identification and downward contrast; and 'negative interpretation of social comparison,' which involves upward contrast and downward identification. They examined this scale amongst cancer patients in The Netherlands (112 patients), and reported that those who were more likely to identify themselves with fortunate others and contrast themselves with unfortunate ones were actually engaged in active coping strategies towards cancer. They concluded that the social comparison interpretations were acting as coping styles. This was because individuals compared themselves to identify how well they were doing or how they were 'coping,' and adjusting with that particular illness. In addition, they positioned the negative interpretation of comparison either downward or upward, as avoidant coping strategies. The interpretations of social comparison dimensions are important to the current study; this is because they illustrate interpretations which people with epilepsy, who are passing urine during an epileptic seizure, may have gone through in their illness. Since there is a lack of objective standards for incontinent epilepsy populations, comparison with downward target may be the best way of perceiving a better feeling. Targets may include elderly people who are leaking most of the time, or patients with bladder infections. In other words, potentially, they may contrast themselves with others who are in a worse situation than they are.

A recent study amongst individuals with spinal cord injury supports the positive effects of interpretation of social comparisons (upward and downward), as coping mechanisms in the adjustment process. In a way positive comparison has a positive impact on the individuals' perspective (Dibb, Ellis-Hill, Donovan-Hall, Burridge, & Rushton, 2014). Previous research has also shown the importance of social comparison as a coping strategy amongst women with breast cancer (Bogart & Helgeson, 2000). This longitudinal study actively investigated the social comparison process, and reported the downward positive comparison as a coping strategy amongst the women and was associated with perceived positive effects. Yet, negative social comparison was associated with an increased uncertainty amongst those patients with lower levels of self-esteem, and lower personal control. Beaumont and Kenealy (2004)

found downward contrast as a psychological adaptive coping strategy amongst elderly people. This study examined the influence of social comparison on the perceived quality of life amongst people aged over 65, amongst London Borough residents. Although the participants of this study were healthy groups, they reported downward contrast as adaptive and functional in increasing their perceived quality of life.

A study of Meniere's disease (Dibb & Yardley, 2006), found support for social comparison effects in adjustment with illness, they highlighted downward positive comparison as the most helpful type of comparison which was associated with positive adjustment and a better perceived quality of life. Similarly, an experimental study of cancer survivors reported those contrasting with a downward target and assimilating with an upward target were associated with a better quality of life amongst patients. However those contrasting with an upward target and assimilating with a downward target experienced negative consequences and a poorer quality of life was perceived (Brakel et al., 2012). The recognition of both upward and downward in comparison directions was also highlighted in an earlier study of a neurological illness (Hemphill & Lehman, 1991). They examined the importance of social comparison dimensions amongst patients with MS and the differences in the function of comparison were reported in their study. It was shown that downward positive comparisons were more likely to occur in terms of physical function based on illness severity. However positive upward comparisons were reported amongst those who used this dimension as a coping strategy to adapt to their illness. A similar study of MS in an older population (Dilorenzo, Becker-Feigeles, Halper, & Picone, 2008), stated the importance of downward positive comparison as one of the most adaptive types of comparison. This qualitative study, reported social comparison as one of the main emerging themes. The authors stated that whilst upward negative comparison affects some of the patients' well-being, downward positive comparison appeared to be helpful as they could maintain a positive self-perception. In addition, Dilorenzo et al. (2008), argued those engaged in downward positive comparison, compared themselves with others without MS and someone with a different disability, such as a cancer patient. This type of comparison, perhaps, helped them to see that there are others in more severe circumstances. This in turn enabled MS patients to make comparisons which were more adaptive. This study has some similarities to one study

that is presented in the current thesis (Study 2), which was a qualitative study on coping and the adaptation process with epilepsy; as well as a direct look at the coping strategies with urinary incontinence. It was revealed that incontinent people with epilepsy were more likely to compare themselves with non-epilepsy groups who had bladder problems or urine trace infections. It could be argued that individuals prefer to make comparison in different domains and perceive positive effects to help improve their own well-being (more detail will be discussed in Chapter 6).

So far, we have understood the mechanism of social comparison. In particular, it was shown how it operates in different conditions, specifically, in chronic illnesses. In addition, the role of social comparison has been identified as an adjustment process to different chronic illnesses. The next section will be more focused on the moderating or mediating factors that can alter the true effects of social comparison.

### **3.5 Mediating or Moderating Factors that may Affect Social Comparison Processes**

Previous research has shown the most common psychological variables effects on the interpretation of social comparisons dimensions are anxiety (Wills, 1981; Bennenbroek et al., 2002), and self-esteem (Wills, 1981; Tennan et al., 2000; Bennenbroek et al., 2002). These two psychological factors can in fact impact the social comparison information interpretation.

#### **3.5.1 Anxiety**

Anxiety has been shown to moderate the effect of social comparison. It can influence the result of social comparison. Earlier, Wills (1981) posited that effective downward comparison (positive) is helpful for stress reduction, such as anxiety. Wills stated that in some studies, anxiety was measured as a dependent variable, in which the affiliations with threatened subjects helped to reduce psychological distress (Wills, 1981). However identification with a downward target produces anxiety, anger and depression. This was because persons were feeling similar to the worse-off target, therefore, inducing a decline in well-being (Arigo et al., 2014). Indeed, it should be

noted that social comparison in turn helps to reduce anxiety, in particular, with seeking affiliation with similar others (Schachter, 1959). In addition, upward identification was found to be associated with reduced anxiety (Taylor & Lobel, 1989), who found cancer patients were more likely to engage in obtaining information from better-off targets as this helped them to feel inspired and to aspire in being more like the target in the future. Reduction of the anxiety was therefore a consequence of having contact with more fortunate others. Bennenbroek and colleagues (2002), found support for the moderating effect of anxiety amongst cancer patients and highlighted the anxiety and uncertainties associated with gathering information through social comparison. They reported that the more negative the self-evaluation and feeling of anxiety and uncertainty about their illness, the more the individuals need for social comparison.

### *3.5.2 Self-esteem*

Self-esteem as a psychological construct has a potential influence on the interpretation of social comparison (Dibb & Yardley, 2006). The level of self-esteem can impact on the social comparison dimensions and their interpretations. Wills (1981), stated that when the subject was threatened, they preferred to compare themselves with others who are worse-off. This type of comparison, in turn, led to an enhancement of their self-esteem. In fact, those with a lower level of self-esteem were subjected to engaging in downward comparison, and felt better as a consequence. However those with high self-esteem were more likely to engage in upward comparison and perceived positive effect; this induced hope and inspiration (Gibbons & Gerrard, 1991).

Similarly, Bogart and Helgeson (2000), found support for self-esteem effects on the social comparison process amongst cancer patients. They reported that a lower level of self-esteem and internal focus on control were engaged in more negative comparison. However the more positive the comparison (downward), it led to an increase in self-esteem. Tennan and colleagues (2000), in their review reported those with high self-esteem were engaged in more downward comparisons. In a study of Meniere's disease those with high self-esteem and control over their illness were engaged in a more positive social comparison (Dibb & Yardley, 2006). Earlier, it was reported that individuals with high self-esteem were more likely to avoid negative

interpretation of either upward or downward comparison (Buunk et al., 1990). They further highlighted that those with a lower level of self-esteem were engaged in negative social comparisons. In an earlier study of Taylor and Lobel (1989), amongst cancer patients, an increase in self-esteem amongst those who engaged in downward comparison was reported. However those fortunate patients who made upward contacts with fellow patients did not show specific progress in self-esteem. Getting information from upward targets could be instrumental in increasing self-esteem (Taylor & Lobel, 1989).

Taken together anxiety and self-esteem have complex interactions. The direction, in which interpretation takes place, depends on the level of self-esteem and anxiety. Those with a lowered level of self-esteem are more likely to engage in downward comparison; as it helped them to reduce the level of anxiety they experienced (Wills, 1981). This is due to the feeling of superiority towards the target which helps individuals to perceive positive feelings, hence comparisons are interpreted positively, as a result.

### **3.6 Conclusion**

This chapter has illustrated the evolution of the Social Comparison Theory in a chronological order. The mechanism of social comparison and how it operates in different circumstances has been discussed. In addition, the social comparison process and its overall application alongside different chronic illnesses, has been explained. The role of this process has also been identified. The interpretations of social comparison dimensions have been described, with specific attention directed towards the dimensions' effects on chronic illnesses and the perceptions of quality of life. This chapter also highlighted the necessity of examining the Social Comparison Theory and its influence on the perception for quality of life in epilepsy as a chronic illness; due to a lack of knowledge in this area. In addition, this review has outlined the Identification/Contrast model of social comparison, which defines the directions in which chronically ill patients interpret the information of social comparison. It has also shown that social comparison dimensions, in fact, can be effective in terms of the

adaptation process to chronic illnesses; where the positive interpretation of such information may lead to adjustment. The most common psychological variable effects on the interpretation of the social comparison process have also been established.

This review highlighted the insufficient research about the role of social comparison processes amongst people living with epilepsy. Although the impact of social comparison processes have been identified in different types of chronic illnesses, this chapter revealed that social comparison might occur amongst people living with epilepsy. However the evidence for this has yet to be confirmed.

The abovementioned literature reviewed the psychological, social and physical impact of epilepsy, the construction of quality of life and social comparison as a theory. It has been recognised there is a gap between the perceived quality of life in epilepsy and the role of social comparison processes in this perception. The next chapter provides a snapshot review from the preceding chapters; in a way how the previous chapters will determine the role of social comparison processes on the perception of quality of life amongst people living with epilepsy in two different countries.

## **CHAPTER 4: METHODOLOGY**

### **4.1 Introduction**

This chapter presents the methodology that applies to the studies in Iran and the United Kingdom. More specific details of the studies in each country are shown in Chapter five, Chapter six and Chapter seven. The previous chapters recognise a gap in literature in terms of the influence of social comparison on the perception of quality of life for people living with epilepsy. It is significant therefore to identify these effects in people living with epilepsy. The following section summarises the preceding chapters and emphasises the necessity of exploring the experience of living with epilepsy.

### **4.2 Summary of the Literature Review**

Chapter 1 indicates the outline for the entire thesis; and identifies the prevalence of epilepsy in developing and developed countries. It also highlights insufficient research on epilepsy in developing countries, which should be taken into consideration. In particular in Iran, the need for more investigation in the field of epilepsy was recommended. This is because epilepsy is a long-lasting illness where individuals have to live with the effects for a lifetime, and involves diverse psychological issues as a consequence. Whilst Chapter 1 explains how substantial epilepsy research can be for developing countries such as Iran, Chapters 2 and 3 illustrate certain factors that are significant to the quality of life and social comparison in different chronic illnesses.

The quality of life chapter explains the concept from different dimensions. It highlights important current reviews in different illnesses. Quality of life is the main outcome measure of this study. The chapter on quality of life also illustrates the ways in which quality of life needs to be measured. It also covers the importance of the adjustment process in the perception of quality of life. Chapter 3 presented the Social Comparison Theory and reviewed its dimensions on how they operate in different types of chronic illnesses. This was because examining the role of social comparison in living with epilepsy is quite a new area. The review of the Social Comparison Theory highlighted the importance of the Identification/Contrast model (Buunk & Ybema, 1997), which proposed people interpret information from comparison dimensions, positively or

negatively. This depends on whether they contrast or identify themselves with the comparison target. In order to measure social comparison, this model was applied in the current study.

### **4.3 Overview of the Research Design**

#### ***4.3.1 Introduction***

The purpose of this section is to provide an overview of the research design that was employed for this thesis. This section will focus on the research question's aims and objectives of the research studies, the rationale for using a mixed-method approach and full rationale for using qualitative and quantitative approaches.

#### ***4.3.2 Research Question***

Does social comparison influence the perception of quality of life amongst people living with epilepsy in Iran and the United Kingdom?

#### ***4.3.3 Research Aims and Objectives***

The principal aim of this study was to examine the role of social comparison on the perception of quality of life amongst people living with epilepsy in Iran and the United Kingdom. In order to do this, the first exploratory study was designed to explore how people with epilepsy experienced their life in Iran and the United Kingdom. Therefore the three main objectives of this thesis are as follows:

1. To achieve an accurate exploration of the patients' experience related to their illness.
2. To explore how people with epilepsy cope with their illness, in particular with their urinary incontinence.
3. To examine the factors predicting the quality of life in people with epilepsy.

In order to complement the qualitative and quantitative nature of the research objectives (1), (2), and (3) respectively, a mixed-method research design was



employed. The first phase of the study used a qualitative method to explore ‘how’ people experienced their life in living with epilepsy. Then results in the first study directed the researcher to develop the second study to investigate ‘how’ people with epilepsy coped with this neurological illness, in particular with their incontinency whilst having an epileptic seizure. Ultimately, the third phase of the study then utilised a quantitative method. This is because the results from the first exploratory study directed the researcher to develop a third study to examine ‘what’ factors can predict quality of life amongst people living with epilepsy.

By addressing the aforementioned objectives, this thesis seeks to build a more comprehensive understanding of how people describe their life and how they perceive their quality of life with epilepsy.

#### *4.3.4 Research Hypotheses*

##### **Hypothesis 1**

The social comparison dimensions impact the quality of life of people with epilepsy:

- 1.1. Downward identification comparison will have a negative effect on the quality of life of people with epilepsy in Iran and the United Kingdom.
- 1.2. Downward contrast comparisons will have a positive effect on the quality of life of people with epilepsy in Iran and the United Kingdom.
- 1.3. Upward identification comparison will have a positive effect on the quality of life of people with epilepsy in Iran and the United Kingdom.
- 1.4. Upward contrast comparison will have a negative effect on the quality of life of people with epilepsy in Iran and the United Kingdom.

##### **Hypothesis 2**

Anxiety will have a negative effect on the quality of life for people with epilepsy in Iran and the United Kingdom.

### **Hypothesis 3**

High seizure severity will have a negative effect on the quality of life of people with epilepsy in Iran and the United Kingdom.

### **Hypothesis 4**

Those with high self-esteem will perceive a better quality of life in Iran and the United Kingdom.

## **4.4 The Mixed-Methods Rationale**

A mixed-method design has been used in this thesis. It is a procedure for collecting, analysing and mixing both qualitative and quantitative data within a study to understand a research issue more completely (Creswell, 2002; Tashakkori & Teddlie, 2003). The rationale for using a mixed-method is that both qualitative and quantitative methods on their own are not sufficient to understand the details of living with a chronic illness, such as epilepsy. The use of qualitative methods was chosen to first explore the way in which people living with epilepsy in Iran and the United Kingdom experience their illness (Study 1), and to understand 'how' individuals with epilepsy coped with their illness (Study 2). The use of quantitative methods was then chosen to examine factors that predicted a quality of life amongst people living with epilepsy in the United Kingdom and Iran (Study 3). Thus by using these two methods, they provided a context for a more complete analysis (Tashakkori & Teddlie, 2003).

The mixed-methodology provides a good pragmatic context for researchers in order to improve their knowledge (Creswell, 2002). The rationale of pragmatism is that both qualitative and quantitative methods are well-matched. Thus statistical and manuscript data, collected consecutively, could be helpful in achieving a better understanding of the research problem (Creswell, 2003). Tashakkori and Teddlie (2003) developed a unit of analysis, for qualitative methods and variables for quantitative methods. This is because these two have been considered the most appropriate features for researchers in order to find an answer to their research questions.

Creswell and Plano Clark (2007) developed three main structures in designing mixed-methods studies. These are *priority*, *implementation* and *integration*. Priority refers to the method, the quantitative or the qualitative, which has been considered as the most important in the study. Implementation refers to whether the qualitative or quantitative data collection and analysis comes in chronological phases, or in parallel stages. Integration refers to the stage where there is a mixing or connecting of the qualitative and quantitative data which occurs in the research procedure (Creswell & Plano Clark, 2007).

#### *4.4.1 Method of Design*

Previous research describes different approaches to combine qualitative and quantitative methods in mixed-methods research (Tashakkori & Teddlie, 2003; Creswell & Plano Clark, 2007). It is known there are three methods available for the mixed-method design. There is 1) the convergent design which refers to collecting qualitative and quantitative data simultaneously, and merging the results of data in the study; 2) the explanatory sequential design where quantitative data is collected first, and then followed by qualitative data; and 3) the exploratory sequential design which refers to collecting and analysing qualitative data first and then results are used to build the following quantitative phase of the study (Creswell, 2013). If the purpose of the current study was to collect both quantitative and qualitative data concurrently then the convergent design would have been used. In addition if the purpose of this study was to use quantitative results to select appropriate participants for the qualitative study, then the explanatory sequential design would have been appropriate. To address the aims and objectives of the current study, therefore, the exploratory sequential design was applied as this study aimed to first explore ‘how’ people experience their life with epilepsy in two different countries, and ‘how’ they coped with their condition. It then examined the role of social comparison statistically. Also, evaluation of the emerging themes from the qualitative study, whether they could be generalised to the aforementioned population, was another purpose of this research. This is a main feature of the exploratory sequential design (Creswell, 2013).

The exploratory sequential design includes two phases of data collection and analysis which is conducted in a qualitative, then a quantitative sequence. The first phase

(qualitative), helps in the development of the quantitative phase (Ivankova & Stick, 2007; Hanson, Creswell, Clark, Petska, & Creswell, 2005). The aim of this mixed-methods design is to use quantitative data to develop and expand upon findings initiated using qualitative data (Creswell & Plano Clark, 2007; Creswell, 2013). Previous research used for the exploratory sequential design in health research areas (Rigg & Ibanez, 2010; Hocking et al., 2014). For example, Hocking et al. (2014) conducted a mixed-method study to explore the perspectives of parents on family-based psychosocial interventions in paediatric cancer in USA. The authors carried out interviews with a sample of 25 parents to obtain direct feedback on psychosocial interventions with the aim of informing future interventions. Based on the interview results, the authors indicated the qualitative outcomes highlighted the significance of considering the psychological reactions of parents, when developing and implementing interventions. To explain this fact in detail, they used records from approved statistics and demonstrated the preference of parents to intervene within 6 months of diagnosis. With mixing qualitative and quantitative methods, Hocking and colleagues thus emphasised that quantitative data is in accordance with the qualitative findings. They further highlighted the necessity of psychosocial intervention, i.e. early in the first 6 months of diagnosis (Hocking et al., 2014).

In this thesis, the first and second studies were the qualitative phases which explored the experience of people living with epilepsy and coping strategies respectively. These were achieved through semi-structured interviews carried out with a sample of people who had epilepsy in the United Kingdom and Iran. Findings from the first study were identified for further examination using quantitative methods. Then, in the third study, the quantitative phase, data was analysed to predict factors influencing the quality of life amongst people with epilepsy. Findings from the qualitative and quantitative phases of the study were then combined in order to provide a contextualised and deeper understanding of living with epilepsy in these two countries. In other words providing a clear foundation of the methodological approach, the next sections will be focused on the rationale for qualitative and quantitative approaches.

#### 4.5 Rationale for the Qualitative Research

Qualitative research is a process of understanding, where the researcher develops a comprehensive view of analyses; and is enabled to conduct the research in a natural environment (Creswell, 2013). Data is collected from people who are deeply involved in everyday life circumstances. In addition, data analysis is dependent on the beliefs that people have on their perception of their lives. Eventually the qualitative research design provides a profound understanding of the issue. The qualitative research approach enables the researcher to gain a detailed subjective experience of people and thereby to gain a broader and well informed insight of the topic being researched (Berg, 2004). Through this approach, the user can gather information about an individual's perception and how they organise and deal with specific issues in their daily lives. In addition, the qualitative research has been widely used to document the experiences of people suffering with chronic illnesses (Reynolds, Vivat, & Prior, 2011).

Yardley (2000), describes good qualitative research as a detailed investigation of different aspects of the topic being studied. The author argues that qualitative methodology is concerned with individual situations and experiences of the people participating in the study. In this regard, qualitative methodology can be considered to be similar to the traditional clinical practice of the doctor-participant relationship where the central prominence is often attached to the two main factors: a) interaction between the researcher and the person who is being studied, and b) the personal and ethical issues arising from that interaction. Therefore Yardley suggests that when carried out correctly qualitative methodology offers a complementary set of exploratory approaches which can bring fresh perspectives about health and illness (2000). In addition Willig (2008), in a similar manner states that qualitative researcher focuses keenly on the concept of 'meaning'. They are interested in understanding how people make sense of the world, perceive the world and hence experience their lives. They also aim to understand the concept of 'what is it like,' to experience a specific condition, such as living with a chronic illness. Hollway and Jefferson (2000), believed that quantitative investigation, which typically involves questionnaires, provide the required statistical information; however, this approach fails to explain in-

depth what the outcomes exact meaning to participants taking part in a survey. In addition, conducting interviews for qualitative research mostly convey an understanding of different individual perceptions and insights regarding the experience of an illness (Radley, 1999).

For the current thesis, understanding the different life experiences of people with epilepsy is important. The qualitative research method aims to document the life experiences of those people rather than using a mathematical or a numerical approach which does not take into account the various types of emotions associated with living with epilepsy.

#### *4.5.1 Philosophical Underpinning*

Qualitative approaches are incredibly diverse and complex, the process involves ‘thematising the meanings,’ which is a general approach across qualitative analysis (Holloway & Todres, 2003). The authors state this approach is grounded in a philosophical background of the ancient Greek idea which refers to the ‘object determines the method by which it is approached,’ (p. 346). In this study, therefore, the focus will be on using the generic approach which is that of using the ‘thematic analyses’ to understand what is living with epilepsy for people. Thematic analysis should be considered as a foundational method for qualitative analysis (Braun & Clarke, 2006). This approach offers an accessible and theoretically flexible method to analyse qualitative data (more will be discussed later in this chapter).

#### *4.5.2 Rationale for Data Collection*

There are several qualitative methods of data collection that could be used. These include methods, such as participant observation, in-depth interviews and focus groups. The most appropriate method of qualitative research is particularly related to achieving a specific type of data (Mays & Pope, 2000). For example, if the main purpose of the current study had been to achieve naturally occurring behaviour in individuals’ typical contexts, then participant observation would be considered as the most appropriate data collection method.

However in the qualitative studies of the thesis, the in-depth interview (Radley, 1999), was deemed the most appropriate method, as the main purpose of these studies was to explore individuals' personal perspectives, experiences and coping strategies. Radley (1999) believed that conducting interviews for qualitative research can provide us with an understanding of different individual perceptions with respect to the experiences of an illness. An interview is not just a process in which information is passively transferred from the interviewee to the interviewer. In fact the quality of the data can be determined by the rapport between the interviewee and interviewer (Radley, 1999). In this thesis since the interview involved achieving individual experiences of illness, it was felt that an interview would allow the development of a rapport between the interviewer and interviewee and so allow in-depth data to be collected. In a semi-structured interview, the approach is more open when compared to a structured interview which often uses a strict set of questions with little room for flexibility (Willig, 2001). Therefore the qualitative data was collected via semi-structured interviews.

#### *4.5.3 Method of Analysis*

In order to analyse the qualitative data, several analysis approaches such as, grounded theory (GT), interpretive phenomenological analysis (IPA) and thematic analysis (TA) were considered. The best type of analysis depends on numerous factors; however, appropriate methods of analysis provide ways of answering the specific research questions (Willig, 2001). In this thesis, the researcher chose the method that best allowed her to answer her research question.

Grounded theory (GT) is a qualitative approach widely used in sociology and aims to generate a plausible and valuable theory about phenomena that is grounded in the data (Glaser & Strauss, 1967). If the main purpose of these studies were to develop a theory and investigate social processes, then GT would have been considered as a method of analysis.

Interpretive phenomenological analysis (IPA) is a phenomenological psychology approach whose prime concern is to understand an individual's experiences or perception within a theoretical framework (Smith & Osborn, 2003). The authors state

the IPA allows researchers to understand how an individual makes sense of their world; it allows researchers to ‘stand in their shoes’ and therefore understand the participant’s perspective. The IPA approach enables an understanding or interpretation of the individual’s thoughts which often is not transparently available from interview transcripts (Murray & Chamberlain, 1999).

Thematic analysis, however, can be a theoretical approach to analysing qualitative data in which the analyst is able to identify patterns of meaning and themes in the dataset (Braun & Clarke, 2006). In the thematic analysis approach, the data is described and organised in detail; thereby a rich thematic description could be achieved in the dataset. Braun and Clarke (2006), argue that thematic approach can give an insightful analysis that answers specific research questions. Since this explorative study’s question is related to how the participants live with their illness and experience their life with epilepsy, thematic analysis was found to be more appropriate without attaching any existing theories; thematic analysis was adopted as the best method of analysis. In addition, thematic analysis was chosen because of the flexibility it provides to the researcher for interpretation, analysis and for determining the various themes from the dataset (Braun & Clarke, 2006). Thematic analysis is not strongly attached to any pre-existing theoretical frameworks and hence can be deployed within different theoretical frameworks (Willig, 2001). This makes thematic analysis a more flexible and transparent method, through which information below the surface level can be unravelled (Braun & Clarke, 2006).

Taken together thematic analysis differs from other analytic methods that search to define patterns across qualitative data, such as IPA and GT. As was mentioned earlier in both methods (IPA & GT), patterns are examined in the data set, but are theoretically bounded (Smith & Osborn, 2003). Although GT is often used in some ways that are more akin to TA than a grounded theory in full-scale, it was nonetheless considered that an explicitly accredited thematic analysis was more appropriate (Braun & Clarke, 2006).

In the qualitative studies of this thesis an inductive approach was adopted as it means the themes identified are strongly associated with the data themselves; and it is possible that a specific research question can emerge from the coding process (Braun



& Clarke, 2006). It is often the case that the inductive approach is a useful method for coding the data without the restriction of trying to fit the data into a pre-defined coding framework. This approach provides researchers a flexibility to generate new themes emerging from the data, rather than testing the existing theories (Pope, Ziebland, & Mays 2000). It is worth noting that the inductive approach has been well documented in health and social sciences studies (Thomas, 2006).

Thematic analysis has six key stages, and the researcher followed these key stages to analyse the data in this study, which were quoted by Braun and Clarke (2006) in following Table 1.

**Table 1 Thematic analysis guideline**

<b>Phase</b>	<b>Description of the process</b>
1.Familiarising yourself with your data	Transcribing data (if necessary), reading and re-reading the data, noting down initial ideas.
2.Generating initial codes:	Coding interesting features of the data in a systematic fashion across the entire data set, collating data relevant to each code.
3.Searching for themes:	Collating codes into potential themes, gathering all data relevant to each potential theme.
4.Reviewing themes:	Checking if the themes work in relation to the coded extracts (level 1) and the entire data set (level2), generating a thematic map of the analysis.
5.Defining and naming themes:	On-going analysis to refine the specifics of each theme, and the overall story the analysis tells, generating clear definitions and names for each theme.
6.Producing the report:	The final opportunity for analysis. Selection of vivid, compelling extract examples, final analysis of selected extracts, relating back of the analysis to the research question and literature, producing a scholarly report of the analysis.

(Braun & Clarke, 2006 p. 87)

- The first stage was the familiarisation stage which includes all of the data and where the transcripts are read carefully, since all transcripts appeared to illustrate a different experience for each participant. By familiarisation, the researcher was able to identify key points and initial ideas from the transcripts.

- The second stage of analysis was obtained through grouping data and refining them into the defined codes. In this step, the paper was split in two columns, and initial ideas from each part of the related data were written in the right hand side of the text. Here the researcher made temporary groups of ideas on the left hand side of the text. This step specified filtering these into identified groups.
- The aim of the third stage was to explore the appropriate themes; this was achieved by making a connection between the gathered codes and the relevant themes. The researcher focused on finding an accurate relationship amongst all data in text.
- In the fourth stage, the themes were carefully re-read by the researcher. The researcher used a thematic map as a tool to depict the range of themes and identify linked patterns within the themes. The aim of the mapping was to enable the researcher to explore the similarities and differences shown on the given themes. Here, the main concern was to give consideration for bringing all outcomes together and gathering all themes together, and then the researcher tried to find links within the themes identified.
- In the fifth stage, all the themes were titled systematically and defined in an appropriate way.
- In the last stage of the thematic analysis procedure, the most vivid themes with rich descriptions were reported. In particular, the researcher avoided recurrent examples in order to provide enough and concise evidence of the themes within the data.

It should be noted that in the qualitative studies of the thesis, quotes have been chosen as examples of comments which were provided by participants. All the mentioned quotes begin with participants' anonymous identifiers (i.e. P1, 2, 31), P1 to P10 refers to participants in the Iranian sample and P11 to P20 refers to participants in the British sample. Numbers 1 and 2 represents female and male participants, respectively. Finally the last number indicates age of the person. All quotes are referenced (i.e. page numbers and line numbers).

#### 4.6 Rationale for Quantitative Research

The quantitative approach enables the researcher to identify the shared strength of multiple variables (Creswell, 2013). In the quantitative research, knowledge has also been claimed based on the numerical data (Creswell & Plano Clark, 2007). A researcher builds the knowledge on a post-positivist perspective, such as concentration on specific variables, hypotheses and the test of related theories. In this regard, an investigator determines variables and related instruments to examine them; in turn results will be highly reliable (Creswell & Plano Clark, 2007). The rationale for using a quantitative approach is that the statistical power of the design allows the researcher to analyse precisely the factors that could influence quality of life amongst people living with epilepsy in Iran and the United Kingdom and to identify the relationships between the variables more accurately (Barker, Pistrang, & Elliot, 1994). In addition, the quantitative research is a way to test theories by examining the relationship between variables of the study (Creswell, 2013).

#### 4.7 Reflexivity

Reflexivity is an important element in qualitative study. It is a good opportunity for researchers to acknowledge their influence and position on the research. It should be noted that a human's impact on the research environment should never be excluded. It was evident that reflexivity, by definition, involves a mindfulness of the researcher's influence in the research procedure, acknowledging that it is impossible to eliminate a human's impact throughout the research (Nightingale & Cromby, 1999). However it is essential to perceive an individual's position whilst conducting research. Reflexivity is about acknowledging the potential influence the researcher may have on, for instance, data collection, analysis and the pitfalls where the researcher was not able to overcome.

The interviewer, as an Iranian female, had been in the United Kingdom for four years; she had not lived in the United Kingdom before and was not familiar with British culture. Therefore she was aware of cultural sensitivity during all the interview sessions with people in the United Kingdom. Reflexivity was achieved as follows; at the beginning of each interview session, the researcher introduced herself properly to

participants and apologized in advance for any language barrier or miscommunication that could have occurred. In addition given that the researcher was an international student; she requested each participant not to use slang during the interview. Also, the researcher remained objective and did not ask biased questions. She asked questions in a way that was not leading or biased and that she took the perspective of a 'naïve researcher' to encourage the participant explain more.

On reflection as two interviews were telephone based conversations, the researcher took notes during the interviews to help her later with analysis. This is because she was not as familiar with the native speakers' local language. At the end of the telephone conversations, the written notes were sent to the participants' provided email addresses for the purpose of accuracy. This action helped the researcher to avoid any misunderstandings or any incorrect interpretations whilst doing the analysis.

Being mindful of Iranian culture, throughout all of the interview sessions, the questions were respectful of participants' religious beliefs, for instance not arranging an interview appointment during Ramadan and in regards to the emerging themes which were specifically social comparison, no direct questions were asked from the participants and no prejudices were exposed during the interview sessions.

In general all of the interviews carried out in Iran were shorter in comparison to those carried out in the United Kingdom. Participants appeared to be conservative, and were less likely to discuss issues in terms of living with epilepsy. It is possible they were adhering to some social norms in their non-disclosure, as they relied heavily on other peoples' opinion of themselves. Therefore the interview sessions for Iranian participants were shorter and limited compared to the duration of interviews with British people. This led the researcher to take more notes during the interview sessions.

In addition, in the first study, during the interview with the fifth participant, she appeared to feel upset. The researcher gave opportunity for her to think and reflect on her experience, and then the researcher managed to create a safe environment in which the participant was able to disclose her experience (Holloway & Freshwater, 2007). Making a secure atmosphere for the participant, avoided any judgmental thoughts, when she disclosed further personal information about herself.

The researcher can confidently reassure that all developed themes emerged from the data gathered and they were not built upon preconceived ideas or beliefs about personal experiences, as the researcher acknowledges comparing and contrasting responses from both Iranian and British participants identified where their similarities and differences are. So the researcher's previous perception about epilepsy did not bias the data collection and data analysis. The following steps have been taken: During data collection, the questions in the interview schedules were not leading. All of the questions were open-ended. No direct questions were asked about social comparison or alcohol consumption. Rather, asking participants to provide the researcher with an example of their experience, allowed the participants to answer how they wished. All of the questions were neutral and unbiased, as the questions were referred to the general experiences of those living with epilepsy. The researcher's approach was also neutral during the interview sessions. As an example, whilst participants were speaking about their problems, the researcher did not express her attitude towards their issues. However she used eye-contact to develop a good rapport with participants. During the data analysis, the researcher constantly looked for new themes. In addition, the researcher continuously checked her coding and theme development with her supervisors.

#### **4.5 Conclusion**

This chapter has provided an overview of the research design engaged in the current study. The main aim of this thesis was centred on examining the role of social comparisons on the perceptions of quality of life amongst those living with epilepsy in both contexts of Iran and the United Kingdom. In order to do this, a study was required to explore how people experience life living with epilepsy and to have a broad view of their experiences and their perceptions. In summary, the three objectives of the study were firstly to achieve an accurate exploration of the patients' experiences related to their illness, to explore how people with epilepsy coped with their illness and to examine factors influencing quality of life in people with epilepsy. In addition the research question and hypotheses of this thesis were provided.

This study utilised a mixed-method approach and adopted an exploratory sequential design in order to complete the qualitative and then the quantitative phases of the

research goals. Since Study 1 and Study 2 of this thesis were qualitative, the researcher employed the qualitative phase for the first two studies and used the quantitative phase for the third study of this thesis.

Although the main research question of this study aimed to answer what influences social comparison had on the perceived quality of life amongst people living with epilepsy, the next chapters have a main role too. First, to *explore* how people experience their life with epilepsy, in addition, to find which factors were important for measurement, when examining the true effect of social comparison, and if they were in fact socially comparing in the first place. Therefore a qualitative study was used in order to understand the wide range of experiences people may have gone through in living with such a chronic illness. Also to explore which people were in fact socially comparing, if so, how and in what way did they do these comparisons? Therefore Chapter 5, (the qualitative analysis from the United Kingdom's sample), was designed to explore the life experience of people living with epilepsy in the United Kingdom. It will be followed with Chapter 6, (the qualitative analysis, Iranian sample), an exploration of the life experiences from people living with epilepsy in Iran.

## **CHAPTER 5: THE QUALITATIVE ANALYSIS OF THE UK SAMPLE**

### **5.1 Introduction**

Living with epilepsy may lead individuals to experience different social and psychological consequences. Previously it has been found that social comparison affects the perception of quality of life in other chronic illnesses in the United Kingdom, such as people with Meniere's disease, and spinal cord injury. It is, therefore, essential to explore how people experience their life with epilepsy as a neurological chronic condition, to see whether, in fact, individuals socially compare themselves in the United Kingdom.

This chapter covers two qualitative studies carried out in the UK. The first study has a general foundation on exploring the life experiences of people living with epilepsy. The result of the first study has led to develop the second study, focusing on the investigation of coping strategies with seizure impact amongst people living with epilepsy in the United Kingdom. The aim of this method, results and discussion each study will be discussed on a separate basis.

### **5.1 Study One**

#### **5.1.1 Aim of the Study**

The main objective of this study was to explore how people with epilepsy experience their life in United Kingdom.

### **5.2.2 Method**

#### **5.2.2.1 Research Design**

In the current study, a qualitative approach was used. For the purpose of this study the use of in-depth interviews as a method of data collection was chosen.

### *5.2.2.2 Participants*

The sample included ten participants (3 male and 7 female), who were members of 'Epilepsy Action' in the United Kingdom. All of these participants met the inclusion criteria for this study; they were required to be aged over 18 years, and have British nationality, with a confirmed diagnosis of epilepsy. The British participants ages were 25 to 52 years ( $M=34.20$ ,  $SD=7.55$ ). The mean years of diagnosis of British participants were 16.60 (min = 2, max = 22) years.

### *5.2.2.3 Sampling Strategy*

The opportunistic sampling technique was applied. The participants took part on a voluntary basis. The semi-structured interviews took place either via a telephone conversation, or an arranged meeting place which was preferred by the participant. Two interviews were completed by a telephone conversation, since the participants lived in Birmingham and Edinburgh respectively. One of the interviews carried out at the participants' home, located in Herefordshire, since she requested the researcher to interview her in her home environment, where she could feel comfortable.

### *5.2.2.4 Procedure*

Ethical approval for the study was obtained from Brunel Psychology Research Ethics Committee (Appendix A). The permission for this study in the United Kingdom was achieved through 'Epilepsy Action' charity (Appendix D).

Prior to participating in each interview, participants were requested to sign a consent form (Appendix E), and they were also issued with a participant's information sheet (Appendix F). By the end of the interview session, participants were offered the debriefing form to obtain more knowledge related to epilepsy (Appendix E). However for those participants whose interview was carried out by telephone, the consent form and information sheet were sent to their email address, which was provided by each participant, prior to interview. When the interview was completed, the debriefing form was emailed to them. All participants were informed about the confidentiality of the procedure and that their name will be kept anonymous. They were also told that they are free to leave at any time.



#### 5.5.2.4.1 Interview Schedule

A semi-structured interview was conducted with individuals living with epilepsy. Since the aim was to gain insights into the lives of individuals, the semi-structured interview approach contained open-ended questions (Willig, 2008) (Appendix H). The interview started by providing a general overview about the process to the interviewees, which helped in making the interviewees comfortable and also to develop a rapport with the interviewer (Willig, 2008). All interviews lasted between 45 and 60 minutes, and all the interview data was digitally recorded.

After providing a general overview of the interview, the interviewees were allowed to ask any questions, if they wanted to. This was followed by asking the interview questions. The first few questions were mainly aimed at getting demographic information about the participants such as age, gender, ethnicity, type of epilepsy, and time since diagnosis of epilepsy. Once the demographic information was obtained, the following questions were asked: ‘What your feeling was when you were first diagnosed with epilepsy?’; ‘How long have you had epilepsy?’ ‘How is your experience of having a seizure? Can you expand on that? How do you find yourself?’; ‘How do you feel after a seizure?’; ‘How often do you get seizure?’; ‘Do you take your medicine regularly?’; ‘What is it like living with epilepsy?’; ‘Do you think epilepsy changed your life since you have been diagnosed with it?’; ‘Are there any other things that are important to you for living with epilepsy?’; ‘What bothers you about living with epilepsy?’; ‘How do you evaluate yourself in interacting socially?’; and ‘How freely can you discuss your illness with family, friends, and others’.

These descriptive questions were designed to achieve general information from participants (Spradley, 1979). No direct questions and leading questions about alcohol or any of the themes were asked during the interview sessions.

## 5.6 Results and Discussion

### 5.6.1 Data Analysis

Each main theme description is provided with illustrations through direct quotes from participants. From the thematic analysis, five main themes were identified. They are: upward negative comparison, seizure impact, limited participation in life, perceived triggers and negative consequences of living with epilepsy which is presented in Table 2. The following themes were extracted from the data which will be presented below:

**Table 2 Outline of each theme and corresponding sub-themes for study 1(UK)**

Themes	Sub-themes
1. Upward negative comparison	
2. Seizure impact	2.1 Fear 2.2 Anxiety 2.3 Urinary incontinence
3. Limited participation in life	3.1 Perception of stigma 3.2 Loss of independence
4. Perceived triggers	4.1 Sleep deprivation 4.2 Alcohol consumption 4.3 Medication attitude
5. Negative consequences of living with epilepsy	5.1 Experience of employment 5.2 Overprotectiveness

#### **Theme 1: Upward negative comparison**

There are some substantial factors that might have an impact on life experiences amongst people with epilepsy. With this in mind, when the participants explained how they experience their life with epilepsy, a majority of them based their feelings on how they were comparing themselves with other people, either with epilepsy or without it in their life. Thus an upward negative comparison theme was developed as the first main theme in this study.

Half of the British participants perceived they did socially compare themselves with others who were in a better situation than them, when they were asked in what way they were experiencing their life. This type of comparison refers to comparison with someone negatively who is perceived to be in better circumstances. 'Feeling jealous,' were common words used by the participants which again indicates their negative upward comparison. Repeated instances of this were found during the interview. Explanations of this comparison were typically situated in the context of sibling relationships and friendships. In the current study, interestingly, the upward negative comparison theme appeared to emerge as one of the most common types of social comparisons, specifically amongst those participants who were diagnosed with epilepsy later in life. It seems that a diagnosis of epilepsy at a late age appears to lead people to feel comparative to others in a negative way; perhaps they are faced with new unclear challenges which they were never used to having prior to their illness. These kinds of challenges might lead them to feel down and embarrassed. Here is an example of the comments that were made in the United Kingdom.

**Participant:**

The following quote from a British woman indicated that she had reached the stage where she was trying to find and interpret a meaning for being ill in her life. It appeared that the nature of her illness was relatively new for her because she did not have any challenges prior to her illness. Therefore she started to compare herself to people who were in a better-off circumstance and did not have epilepsy. This comparison eventually made her feel inferior. Her epilepsy started when she was 20. Accepting that she was now an ill person appeared to be difficult for her, because she was never known as a person with epilepsy previously having been diagnosed with epilepsy at age 19. Therefore she was not prepared even to talk about her illness to anyone. Jealousy was a key emotion displayed by her since her drinking habits had to change after the diagnosis. She began to compare herself with others who could drink freely. In particular, the comparison was situated in her sibling relationship, where she compared herself to her sister who could drink. This made her feel jealous. In general, facing new challenges, such as, not being able to drink alcoholic beverages, led her to feel stressed out and irritable because she also experienced peer pressure when in the company of friends but could not drink and feel a part of the group.

P17.1.25:

*I don't mind here but all my friends in back home are well, and you all the time you get why? Why you've got to live with this in there?! I know it's quite selfish in some way, but I ask myself why they living their lives.... but I have to watch every little thing.... It took me three years... to talk about it. I get very jealous of my sister. I'm jealous of people who can drink, when you go out for drinking, I feel really wish I could drink. (page7, line 194-204)*

## **Theme 2: Seizure impact**

Seizure impact emerged as the second main theme from the dataset, there were several factors that impacted seizures amongst the participants and all of which have affected their lives seriously. The factors included: fear, anxiety and urinary incontinence. In the current study these factors have been developed as sub-themes which will be demonstrated in some examples of comments which were made by British participants.

### **Sub-theme 2.1: Fear**

In the interviews, four participants expressed fear, in particular their fear was an established fear based on having the next seizure, especially in the presence of others. This is because they did not know when they would experience their next seizure. In particular some of the participants explained how they were scared of getting their next seizure, whilst they were only just recovering from the previous one. Here is an example of the quotes which were made by a participant indicating the fears they experienced.

#### **Participant:**

A British male participant expressed his fear relating to his seizures; especially those he experienced in public, since his job as a dance trainer made him come face to face with the public. He reported having a sad experience where once he developed a seizure in front of his audience which made him feel negatively about himself. He further explained about an incident where his fear of a seizure recurrence became such that it even led him to assume he was in an actual seizure mistakenly and caused him

great discomfort and distress, especially as he is a dance trainer. It appears that he was scared of developing a seizure in front of other people, and perhaps the perception of shame and embarrassment made him feel worried about having his next seizure in public.

P13.2.33:

*I was training in front of people and suddenly I did some twisty movements, I fell down on the floor. The worst thing was peoples' thought that it was still part of the dance. Having seizure in others' presence is quite embarrassing (...), suddenly you're cut out for a moment, and will come around with a resistant headache and having kind of fear in your mind, 'Ok, when is the next one?!' Or sometimes after a seizure I feel extremely tired and I'm like 'oh, did I have another seizure (page5, line109-120).*

### **Sub-theme 2.2: Anxiety**

Anxiety refers to being worried about something with uncertain consequences (reviewed in Chapter 1). During the study, it was perceived that four British participants felt anxious as a result of their seizures. In particular, some of them experienced anxiety as a consequence of the unpredictable nature of their seizures which may happen in public because they did not know when or where they were going to have a seizure. The symptoms of feeling anxious were based on experiencing a specific type of aura or, 'a feeling of butterfly in my stomach'. It is possible that amongst people who were diagnosed with epilepsy, psychological distress might be associated with the epilepsy, or epilepsy itself might lead them to feeling anxious. Here is an example of the quotes which were made by the participant to indicate the feeling of anxiety in the United Kingdom.

#### **Participant:**

The following quote is from a female participant who spoke about her anxiety. She said her anxiety was linked to the fear of the severity of her seizure. From her responses it appears that factors such as anxiety or being in a stressful condition would influence the severity of her seizures. She also commented on having experienced the

strange feeling of ‘butterfly in her stomach’ which made her even more anxious and scared. Experiencing this strange feeling in her stomach, led her to yell afterwards.

P17.1.25:

*I feel like epilepsy is my worst enemy; and I often get anxious (...). When things have got on top of me, I feel ‘butterfly in my stomach’ which is a bit annoying, scary. It’s just kind of a sense. Sometimes if it gets worse, I start scream and shout everyone around me (page13, line400-410).*

### **Sub-theme 2.3: Urinary incontinence**

One common issue seen amongst a few of the participants in this study was the issue of urinary incontinence. In the current study, three British participants talked about passing urine during their seizures. Urinary incontinence can have severe psychological and social impacts on peoples’ lives, (reviewed in Chapter 1). The psychological stress of dealing with urinary incontinence appeared to act as one of the main reasons for experiencing anxiety amongst the participants. It can be deduced that those participants who were passing urine during their seizures, felt anxious in terms of wetting themselves because shame and embarrassment might be associated with it. Here is an example of the comments which were made by a participant in the United Kingdom. The psychological stress was not limited to anxiety; some of the participants expressed their fear in correspondence with urinary incontinence. However, this fear was not just limited to developing a seizure; it also included the fear of passing urine as it comes alongside the seizure which made some of the participants even more worried, perhaps due to the shame and embarrassment attached with this somatic symptom. It appears that the fear of a seizure recurrence and fear of passing urine overlapped in some cases.

**Participant:**

The following quote is of a British male participant. He explained his negative experience in terms of passing urine during the seizure in public, where he is ashamed of himself especially when his mum had to help him change his clothes. He explained how being incontinent made him imagine himself as ‘an old man’. He described it in terms of a feeling of leaking and therefore as a consequence, felt embarrassed.

P14.2.35:

*I can't stop my urine during seizure but the thing is I never remember what exactly happens to me. Once it did happen (...) when I woke up my mom was changing my trouser, it's just felt crap, because you just feel like 'an old man' you can't stop your urine and the feel like leaking (page4, line 75-82).*

**Theme 3: Limited participation in life**

Epilepsy affects some people's lives and it does so in different ways. This theme which was observed in the dataset discusses various limitations participants may face in their daily activities. Factors, such as the perception of stigma and loss of independence were considered as sub-themes. These factors were seen as barriers which restricted participants in their daily activities.

**Sub-theme 3.1: Perception of stigma**

Two participants confessed they have received unpleasant attitudes from people in public. They spoke about the negative attitudes in society towards people with epilepsy. The current sub-theme refers to participants' interaction with others and how they have been treated negatively, by other people without epilepsy. Below is an example of comments made by a British participant.

### **Participant:**

This British female participant shared an undesirable experience she had to face at a night club. Since she had photosensitive epilepsy, she was extremely sensitive to flashing lights, which may be a trigger for her resulting in seizures. It appears that an encounter with flashing lights in a club, made her feel worse, which led her to sit down. She explained how she became embarrassed when she was forced to leave, as it was mistakenly thought that she had slept for a while. She further described how humiliated she felt because she wanted the lady to believe her, that she didn't mean to do anything wrong, and even she explained herself to the lady, informing her that she had epilepsy. However it seems that with the stigma associated with epilepsy, the lady did not care much about her. This participant's responses indicate how others' negative attitudes can result in humiliation and shame for individuals with epilepsy.

P15. 1.30:

*I've had odd experience from strangers (...) I was in a club (...) all these flashing lights came on which started a lot of epileptic activity in my brain. The woman (...) kept pushing me and saying, I couldn't sleep here and I had to leave. I was absolutely furious with her; I just started swearing at her and said you know "I have got epilepsy." "I am not sleeping; I am just resting my eyes." But she just (...) was really nasty (p.16, line 515-546).*

### **Sub-theme 3.2: Loss of independence**

One of the major concerns expressed by participants was not being able to lead a completely independent life. This is mainly due to the effects of having a seizure. Half of the participants said they were not able to live a satisfactory independent life. Hence, loss of independence as a sub-theme emerged. British participants considered, for example losing their driving license as a huge barrier which limits their independence. By UK legislation, people with epilepsy are not allowed to drive a car, even if they have a driving licence they might lose it (reviewed in Chapter 2). In the interviews, many British participants said the 'inability to drive' was one of the main reasons for them to be dependent on others. Here is an example of the comments which were made in the United Kingdom to express the difficulties people with epilepsy face due to their dependency on others.



**Participant:**

A British female participant expressed her she felt being dependent on others, how it was humiliating for her because she felt that she was totally dependent on others. It appears that the inability to drive had been an inconvenience and a disappointment to her, since being unable to drive prevented her from applying for jobs in her chosen career and also not being able to live in the countryside as she could not drive. It seems that if she had a driving license, it would have helped her to have a more independent lifestyle where she could apply for her dream job without feeling embarrassed. However according to the law in the United Kingdom, a person diagnosed with epilepsy, is not allowed to have driving license. She further compared herself to people who could drive which made her feel inferior. In other words, she compared herself to people in a better-off state, (upward negative comparison).

P11.1.25:

*My boyfriend doing sponsors skydive for (...) cats; because of epilepsy, I can't do it. (...) but every job I see, says, "Driving licence essential." I'd love to live in the beautiful countryside, but I can't because I don't have a car. It is literally impossible and I can't be as independent as I want to be (...). But it, what it most effects is driving, when I see people drive, I become very jealous and I would say, that's what affects me the most (page6, line 137-152)*

**Theme 4: Perceived triggers**

During the interview, many participants placed emphasis on specific factors, such as lack of sleep, drinking alcohol and not taking medicine that may cause them to develop more seizures, (reviewed in Chapter 1). In this section the research discusses these types of triggers. The main theme referred to as 'perceived triggers,' is comprised of the following sub-themes: 'sleep deprivation', 'alcohol consumption' and 'medication attitudes'.

**Sub-theme 4.1: Sleep deprivation**

This sub-theme was developed from discussions about getting insufficient sleep which could be a trigger for seizures. It appears that sleep was a major problem for many participants. Participants often made a link between the seizure frequency and having an insufficient amount of sleep. Four participants explained how inadequate sleep was

a major issue for them to tackle. Sleep deprivation is important since the participants felt that it makes the occurrence of seizures more likely, and this seems to be the case for them. Some of the participants explained how sleep deprivation worked as a trigger for seizure recurrence since it made them have a seizure the following day. In addition, participants spoke about the side effects of the medication they used which led them to experience insomnia in some cases. Staying awake for some consecutive days was perceived to be a cause in developing more seizures. Here is an example which was made by a participant in the United Kingdom.

### **Participant:**

The following quote refers to a British woman who believed that sickness, insufficient sleep, and a high fever were the main triggers of her seizure onset. She described an undesirable experience that she had when she was flying in an aeroplane during which she had a seizure. The seizure happened due to sleep deprivation the day before her flight. She believes her seizure onset was associated with inadequate sleep and therefore, faced a bad experience.

P16.1.52:

*I'm getting seizure when I'm sick and sleep deprived (...); mostly sleep deprivation happens to me because of traveling. Once I was on aeroplane, I had seizure; I started to see flashing lights, colours, leaving my body very quick (...) the night before flight I hadn't had enough sleep and it pushed me to get seizure the next day in flight (page8, line174-182).*

### **Sub-theme 4.2: Alcohol Consumption**

Half the British participants commented that they felt alcohol did affect their seizure frequencies and caused them to develop more seizures. No direct question was asked regarding the alcohol consumption; however, this sub-theme emerged when participants expressed their negative feeling about their seizures. Drinking alcohol posed as a trigger which they felt had a significant impact on the frequency of their seizures amongst the participants from the United Kingdom. In other words,

participants considered alcohol consumption as another causal factor which they felt triggered their seizure episodes. Here are examples of the comments which were made by British participants.

**Participant:**

A British female participant explained how alcohol triggered her seizure onset, which in turn affected her job as she explained about the difficulties she faced at work. It seems there is a link between her seizure frequency and drinking alcohol, as she felt she developed more seizures after she drank alcohol. She appeared to feel unsatisfied because she was not allowed to drink alcoholic beverages.

P12.1.32:

*It's just frustrating because you can't drink; if I drink alcohol, it really increases my seizures a lot. So, certainly drinking lots of alcohol is really bad. When I was getting tonic clonic seizures I was getting really bad side effects from alcohol, like more seizures which was really difficult trying to get on work. So, that was really horrible (page4, line81-88).*

**Participant:**

A British male participant, perceived to be a frequent alcohol drinker prior to his illness, but since he was diagnosed with epilepsy, he was aware that he should stop drinking alcohol. Further, he did not want epilepsy to restrict his social life. Even though he was aware that alcohol would increase his risks of developing a seizure, he often was subdued by the peer pressure and he did not restrict himself in consuming alcohol. As a result, he had strange feelings of getting seizures the day after he consumed alcohol. However, he commented that being unable to drink alcohol did restrict him socially and it might even lead him to lose his friends. He faced peer-pressure and had to pretend to behave in such a way his colleagues believed nothing had happened to him.

P14.2.35:

*I used to drink. But since I've diagnosed, I try to stop it. I'm doing my best to avoid it. When I'm out with colleagues it's quite tough to see them ordering. Obviously when you are not drinking! You get why? It's just like losing your friends (...). But I was out drinking (...) and the morning after, I was kind of weird, like going to have fit, then I had actually (...)* (page3, line40-49).

### **Sub-theme 4.3: Medication attitudes**

Anti-epileptic drugs are special drugs used for the treatment of epilepsy (discussed in Chapter 2). It seems that whilst medicines have benefits, they have their own potential side-effects which in turn could affect people's quality of life. People could react to the medicines in different ways. Three participants felt they had negative experiences when they were on medication; sleeplessness, tiredness, and experiencing mood swings were the most common experiences from participants in the United Kingdom. Here are some examples of the comments which were made by participants in the United Kingdom.

#### **Participant:**

A British male participant as demonstrated below, talked about encountering mood swings as a side-effect of the medication. He felt that Keppra (epilepsy medicine), made him rage. He also felt that unlike his desire, he has had unstable mood changes since the medication could change his behaviour easily from being a rude person to experience tiredness. On the other hand, being diagnosed with epilepsy at a late age, led him to encounter apparent changes in his ordinary life routines for instance, not getting as much sleep as he used to or enough of it. He pointed out that his previous anti-epileptic drug (lamotrigine), made him stay awake for two days, which led him to avoid taking the medicine, which in turn made it more likely he would develop a seizure the following day. It could be said that not taking the medication and developing a seizure is a side-effect of the medication, where people perceived having less of a desire to take their medication. The quote below expresses his feelings:

P18.2.33

*I'm on medication since 12 (...), when I was younger; I was going off to sleep solidly. But since I've got epilepsy, it's sort of waking up and unable to back off to sleep make me crazy. There is a 'keppra rage' you can get very bad mood swing, I can be rude person without wanted to be. When I was taking lamotrigine, I was awake for 48 hours, it gave me insomnia, I ignored it for a night and the day after, I got fit (page8, line183-193).*

### **Participant:**

Another British female participant gave negative feedback in regard to her medication, and it was similar to the previous participant who had complained about the side-effects of his medicine (Keppra), this participant was also on the same medication. The participant was unhappy with Keppra and she indicated that it had a negative influence on her mood in the way it changed her behaviour. She appeared to perceive negative outcomes; however sometimes it seemed that she was in doubt if her behaviour was linked to her medication, or if it was related to her own behaviour. In other words, it seems that she felt uncertain whether her mood was impacted by her medication, or if it was her actual behaviour.

P20.1.40

*It was awful yeah. It felt like having bi-polar, that's what it felt like because one minute, I'd be fine, and then the next minute I would be like a banshee. Like an absolute nutter, going off like really, really angry all the time. But I will always have this question, the question is does it rule me, it does and it does not (page11, line 315-320).*

### **Theme 5: Negative consequences of living with epilepsy**

Living with epilepsy is challenging and might lead people having demanding times in their lives. Some participants had encountered barriers such as the experience of losing their jobs and others felt overprotected by their families. Negative consequences of

living with epilepsy as a fifth main theme is comprised of two sub-themes: ‘experience of employment’ and ‘overprotectiveness’.

### **Sub-theme 5.1: Experience of employment**

Three British participants felt they faced challenges regarding their employment status. They spoke of negative experiences whilst being employed which has been considered a barrier in their life. Some of them felt they were discriminated against and as a result, lost their jobs; others felt even in the interview session they were rejected because of their epilepsy. Here is an example of the comments made by a British participant.

#### **Participant:**

Some of the British participants reported negative experiences in their workplace as well. Being unable to get a job was one of the concerns of British participants. For example, in the following quote finding a job for a British woman had been very challenging. It seems that she had to explain her illness in the interview session, which after disclosing the illness, may have influenced her being rejected after the interview session. She expressed that she felt discriminated against:

P19.1.35:

*Going through the application process is stressful (...) I've been trying to get a job. Once I was invited for an interview, at the end I had to mention them 'Oh, by the way I've got to tell you that I'm epileptic'. I couldn't get that job (...) still we have employment discrimination (page7, line166-173).*

### **Sub-theme 5.2: Overprotectiveness**

This sub-theme emerged as another negative point of living with epilepsy amongst the British participants. Three participants felt overprotected by their families, especially by their parents. Some of the participants expressed their negative feeling towards an overprotective family, specifically their parents as they felt they have been treated like a ‘kid’. This appears to have a negative psychological impact on them. Here is an example of the comments made by a participant in the United Kingdom.

### **Participant:**

The following quote is from a British man who felt unhappy about being closely observed by his family, particularly by his mother. He was diagnosed with epilepsy when he was in his 20s. His family may have perceived that he could not regulate his life because he was used to being an independent person, and the illness was unfamiliar to him. As a mature man, he perceived a negative effect because he felt that he had been treated like a child, which was not a good feeling. The feeling of being protected continuously by someone appears to be a negative consequence of living with epilepsy. Since his diagnosis with epilepsy, his life circumstance has changed dramatically and those changes have led him to feel overprotected by his family.

P13.2.33:

*I guess peoples' concern is not acceptable for me! I don't like the fact that people are thinking about me, just freaks me out. I was over protected a lot like a child. Nearly for 10 years I couldn't do anything, I used to be very independent person, I'm very unhappy. Then top off that, you've your own emotions and it's hard sometimes to feel like you have been observed 'constantly' by your family (page6, line137-147).*

### **Discussion**

The current study aimed at answering the research question, 'In what way do people with epilepsy in the United Kingdom experience their life with epilepsy?' This has been achieved through interviews with the participants from the United Kingdom, which led to the development of the various themes whilst discussing the participants' experience of living with epilepsy. The investigations into the experience of living with epilepsy; focusing on social comparison, to the best of the researcher's knowledge, have not been previously reported. Therefore, this study is novel, as it is the first attempt to explore how people experience living with epilepsy.

### *Social comparison influences on chronic illness*

Overall, the findings of the current study appear to support the Social Comparison Theory (Festinger, 1954); which states that individuals tend to compare themselves in unclear circumstances. More specifically, individuals when in threatening circumstances, for self-evaluation purposes tend to carry out comparison with others (Taylor & Lobel, 1989; Wills, 1981; Buunk et al., 2006). The findings are in line with Festinger's (1954) statement about a desire for self-evaluation to determine the most appropriate behaviour for ourselves. Festinger believed that this could occur via objective standards. This theory offers an explanation for people living with epilepsy. Since the objective standard of well-being is missing, individuals in order to obtain information, require comparison technique for self-evaluation (1954). The social comparison process also can be implicated in the interpretation of health threats (Heidrich & Ryff, 1993). In relation to epilepsy, it is a chronic illness which may cause disruption and affect an individual's everyday life; it is possible that in such circumstances participants will evaluate themselves by socially comparing. The outcomes of the study showed that individuals appeared to socially compare themselves to better-off targets and perceive negative feelings as a consequence, feelings such as being down or disappointed. This supports the Identification/Contract model (Buunk & Ybema, 1997) comparing oneself with fortunate individual can be interpreted in both a positive way and negative way. The comparison depends on whether someone contrasts or identifies oneself with the target group. Contrasting with someone better-off leads to feel dejected. This is because they felt dissatisfied and dissimilar to their target group (White et al., 2006). It can be said that British people with epilepsy rather than identifying with better-off targets contrasted with fortunate others, which in turn, led them to perceive negative effects (Buunk & Ybema, 1997). The findings are unique, as no previous study found support for the social comparison influences amongst those living with epilepsy, in particularly, in the UK.

There is evidence for upward negative comparison in other chronic conditions. As an example, previous literature found support for the negative impact of social comparison (upward), and its association with depression (Heidrich & Ryff, 1993). Evidence for this is provided by Buunk et al. (2006), amongst those with a spinal cord injury, where depression was perceived as a consequence of an upward contrast



comparison. In addition, Bogart and Helgeson (2000) found support for negative social comparison (upward), amongst women with breast cancer and reported that whilst the downward positive comparison was more likely to be associated with positive effects, upward contrast were linked to negative psychological outcomes. This is consistent with the current study's findings, which found that those British people who were engaged in upward contrast comparison perceived negative consequences. This was confirmed earlier by Wilson et al. (1997), who examined the social comparison impact amongst individuals with sickle cell disease. They suggested that patients tend to make comparisons towards their peers and perceive depression as a negative psychological consequence. They further argued that since the nature of the illness consists of recurrent pain, patients who did comparison to fortunate others, experienced high levels of depression and long term pain. It is known that a better health status was associated with less upward negative comparison (Bogart & Helgeson, 2000; Dibb & Yardley, 2006; Dibb et al., 2013). Therefore it can be speculated that the more engagement in upward negative comparison, the more the participants are going to perceive depression. Previous research also highlighted the importance of social comparison dimensions amongst particular chronic illnesses, such as Meniere's disease (Dibb & Yardley, 2006), cancer (Buunk, et al., 1990; Bellizzi et al., 2006), Multiple Sclerosis (Hemphill, 1989; Dilorenzo et al., 2008), and spinal cord injury (Dibb et al., 2013). However this study is unique, as no prior study in the UK showed the social comparison influences, in particular feeling negative after comparison to fortunate others (upward contrast comparison), amongst people living with epilepsy as a chronic illness.

There was no upward positive comparison seen in this study. This could be referred to the identification process, in that people could have linked their situation to that of a target in a way that they could inspire them to feel positive and that they will be healed similar to the target (Gibbon et al., 2000; Bennenbroek et al., 2002; Brakel et al., 2012). However this dimension was not evident in the cases of the current study; downward comparison dimensions, neither positive nor negative emerged from this study. Looking at participants, how they compare themselves to better-off others most likely people without epilepsy (i.e. people who could drink and drive); would explain why comparing to someone worse-off did not emerge in this study.

### *Psychological consequences*

In the context of epilepsy research, this study found support for perceiving anxiety and fear as consequences of an epileptic seizure. This is in line with previous studies which highlighted that individuals with epilepsy are more vulnerable to the psychosocial impact of epilepsy than the general population (Baker, 2002; Baker et al., 2005; Taylor et al., 2011). Feeling fearful and anxious is grounded in the unexpected nature of an epileptic seizure (Jacoby, 2000; Jacoby et al., 2005; Baker et al., 2013). In addition, it is known that fear of a seizure is associated with social isolation; as patients are less likely to be partaking in social activities (Ekinci, 2011). This may lead them to give rise to anti-social behaviours (Hills, 2007). It can be argued that some of the participants felt they were living with uncertainty which derived from the unpredictable nature of their seizures (Stanton et al., 2007; Baker et al., 2013). In addition, a feeling of lack of control in regard to their seizures was more likely to lead to anxiety (Gaitatzis et al., 2004; Taylor et al., 2011). The findings provided support for the study of Baker (2002); indicating individuals with epilepsy experience uncontrollable and unpredictable seizures and an inability to control them may result in psychological consequences. This might also be related to clinical implications in relation to the unpredictable nature of a seizure in living with epilepsy (Jacoby et al., 2005; Baker et al., 2005). Anxiety has been previously evident as one of the attached phenomena to epilepsy (Baker, 2002; Vazquez & Devinsky, 2003; Ekinci, 2011). The evidence for this is provided by a study of Gaitatzis et al. (2004); highlighting the prevalence of anxiety in epilepsy, due to the unpredictable nature of seizures, which affect approximately 10-25% of people with epilepsy. The impact of anxiety with epilepsy was also reported in Johnson et al. (2004), where their research investigated the effects of anxiety and depression on quality of life in epilepsy; anxiety, in particular, was highlighted as an extra burden in living with epilepsy. It can be understood that fear and anxiety are an overlapping phenomena which has been attached to epilepsy (Jacoby, 2000; Baker et al., 2005). In addition, Goldstein and Harden (2000), argued that having a profound understanding of anxiety will aid the investigation of the neurological and psychological mechanisms found within

epilepsy. The prevalence of anxiety was well documented in epilepsy (Beyenburg et al., 2001; Mula & Sander, 2007).

### *Somatic consequences*

This study, unexpectedly, found that some British people with epilepsy may experience the passing of urine which is attached to their seizure. Urinary incontinence has a chronic comorbid sign with epilepsy (Télliez-Zenteno et al., 2005; Brigo et al., 2013). This somatic symptom has received clinical attention in literature based on epilepsy (Peguero et al., 1995; Dworetzky et al., 2005; Timary et al., 2002); and in other studies of general populations (Sinclair & Ramsay, 2011; Abrams et al., 2010). This particular finding is consistent with some aspects of other reported studies; yet, however there is no sufficient literature related to the psychological outcomes of urinary incontinence in epilepsy. The experience of anxiety was not only limited to the unpredictable nature of a seizure, but it was also linked to passing urine during an epileptic seizure. This could mean the more an individual passes urine during a seizure, the more the individual will perceive a feeling of anxiety.

Urinary incontinence has been evident in accordance with anxiety in community-dwelling adults (Bogner et al., 2002; Stauber et al., 2007). It was suggested that urinary incontinence as a common condition may lead to several psychosocial consequences, such as shame, embarrassment, social isolation, anxiety and depression (Molinuevo & Batista-Miranda, 2012). The high prevalence of anxiety amongst people with urinary incontinence has been evident. This is because incontinent people, in particular elderly individuals may not have easy access to a toilet; this makes them anxious just in case they pass urine in public (Bogner et al., 2002). However it should be acknowledged that psychological consequences of urinary incontinence in epilepsy may differ from the effect of this somatic sign in the general population. This is because people with epilepsy only pass urine whilst having a seizure, whereas the general population, such as elderly people may experience this issue for a whole day.

### *Social consequences*

This study found support for the perception of stigma amongst those living with epilepsy in the United Kingdom. It became evident that stigma has been prevalent in European countries, (Suurmeijer et al., 2001; Baker et al., 2005). Previous studies showed that the more feeling stigmatised an individual living with epilepsy, the poorer psychosocial functioning was perceived (Jacoby, 2000; Smith et al., 2009). Consistent with this is the current study showing that some of those living with epilepsy appear to perceive stigma within society as a whole. Recently a study involving individuals diagnosed with epilepsy in the United Kingdom, (Taylor et al., 2011), examined the level of stigma and its impact on quality of life. 54% of patients felt stigmatised; the high level of stigma was reported amongst those who perceived a lowered quality of life. Previous studies confirmed the negative impact of stigma on quality of life which resulted in social withdrawal, (De Boer et al., 2008; Smith et al., 2009; Baker et al., 2005). It is known that the social difficulties of living with epilepsy, such as stigma, can pose much more problems than a seizure itself, (Jacoby & Austin, 2007). This leads to a consideration of stigma as a psychosocial burden of living with epilepsy, (Baker, 2002; Baker et al., 2005). It can be said that epilepsy is not just a neurological illness but also it is a social label (Jacoby et al., 2005). It could be argued that living with epilepsy appears to lead people to experience social isolation and feeling marginalised within society seems to be the case in living with epilepsy.

Previous research showed that people with epilepsy have restrictions in their regular life activities (Livneh et al., 2001), which, in turn, may lead them to having some restrictions in their life. This is in line with the current study where those with epilepsy felt they had no independence in their life, and they were more likely to be dependent on others in many aspects. Lack of autonomy in living with epilepsy has been evident in previous studies (Jacoby, 2000; Bishop & Allen, 2003; Kerr et al., 2011); where it was associated with social barriers, such as transportation, insufficient freedom, and unemployment. It appears that epilepsy challenged an individual's life and frustrated them on a daily basis, since they are subject to some kinds of limitation which in turn could lead people to lose their independence in life (Marinas et al., 2011). Unemployment has been found as a field with significant problems for individuals with epilepsy for more than a decade (Smeets et al., 2007). In line with this, this study

found that a great number of British people experienced working restrictions. In addition, it is known that unemployment rates amongst those with epilepsy is associated with feeling stigmatised and related psychological distress (DiIorio et al., 2003; Harden et al., 2004; Lee et al., 2005; Smeets et al., 2007). The findings were supported by a research study conducted in the United Kingdom which indicates that patients of epilepsy have driving restrictions which could be banned; however, it can be restored after a specific period after remaining seizure free (Jacoby & Austin, 2007). It is worth noting that in the United Kingdom, the 1995 Disability Discrimination Act (DDA), has been legislated and which protects disabled people from discrimination in the field of employment (Gooding, 2000); the author expanded on this and documented the short versions of this legislation for people with epilepsy. Employment, obtaining a driving licence and independence are the highest concerns for those living with epilepsy in the Western world (Marinas et al., 2011). Earlier, Livneh and colleagues (2001), found support for this and highlighted the lack of independence in terms of limitation in life experiences, such as housing restrictions when living with epilepsy. Kerr et al. (2011), systematically reviewed the qualitative literature of epilepsy research and stated a loss of freedom and independence as the most reported issues for people with epilepsy, as they have to change their life plan. This was because they have limited options to choose. Independence and autonomy have also previously been highlighted as the quality of life domains in epilepsy, in short the stronger the feeling of being dependent on others, the worse the quality of life was perceived amongst epilepsy patients (Livneh et al., 2001; Bishop & Allen, 2003). Applying to this study, it can be argued that some of the British people referred to a discrepancy between their current condition and their anticipated situation as they did not have enough independence.

### **Perceived triggers**

A clinical review of epilepsy highlighted the interaction between sleep disturbance and epilepsy (van Golde et al., 2011); a significant poorer quality of life amongst epilepsy patients with a sleep disorder was reported. Consistent with this, the current study found that those with epilepsy appeared to experience more seizures due to insufficient sleep. In other words, sleep deprivation has been considered as a potential trigger which, in turn, makes seizures more likely to occur. Malow (2004) found

support for the negative effects of sleeplessness on seizure frequency, and stated that insufficient sleep acts as a facilitator of epileptic seizures. It is known that there is a complex interaction between sleeplessness and epilepsy (Matos et al., 2010; Bazil et al., 2002). It can be argued that frequent seizures and seizure severity may not lead to behavioural problems, yet sleep disruption may have a significant role in behavioural difficulties amongst those with epilepsy (Becker et al., 2004; van Golde et al., 2011).

This study also found that alcohol consumption could in fact make seizures more likely to happen amongst the people with epilepsy in the United Kingdom. Consistent with literature, previous studies confirmed the alcohol dependence amongst people with epilepsy (Samokhvalov et al., 2010), and the negative impact of alcohol consumption on seizure thresholds (Hillbom et al., 2003). It can be argued that insufficient sleep and alcohol consumption are the most common associated factors with high seizure frequency amongst people living with epilepsy. The suggestive findings were confirmed by Malow (2004), who indicated that diagnosing with generalised tonic-clonic seizures, and being sleep deprived, along with alcohol consumption; all make the epileptic seizures more likely to occur (Pisani et al., 2002).

Although recently with the great help of medication, seizures are more likely to be controllable (Perucca & Tomson, 2011), the AEDs' side-effects should not be neglected (Ortinski et al., 2004). This is consistent with the current study, where a few of the British participants reported side-effects from their medication. They appeared to feel ambivalent about taking medication. This could explain potential side-effects which may result in ignorance (Kerr, 2012). This finding is in line with Ortinski and Meador's (2004), study where the authors highlighted the positive and negative effect of AEDs' on mood amongst individuals with epilepsy; this could provide extra attention to choose the most appropriate medication for treatment. They further reported cognitive and behavioural impairment as a result of AEDs' side-effects. In addition, Perucca and Tomson (2011), stated that when seizure freedom is not going to be a reality, the final goal should be focused on providing a better quality of life for epilepsy patients. This can be achieved by a compromise between experiencing less seizures and the burden of AEDs' side-effects.

## 5.7 Conclusion

Overall, this study indicates that feeling negative after comparison to someone better-off may be associated with perception of having a poorer circumstance in comparison to people without epilepsy in the United Kingdom. This may lead to perceive negative consequences, such as embarrassment, shame and disappointment amongst British people living with this chronic illness. However, this study is unique in exploring the upward negative comparison amongst those living with epilepsy; as to date literature has focused on the Social Comparison Theory in other chronic illnesses.

In addition, it was revealed that epileptic seizures have potential negative consequences, since the nature is unpredictable. Psychological consequences, such as fear and anxiety, were perceived as negative outcomes. Living with epilepsy was not confined to psychological consequences. It was also found that individuals with epilepsy perceived an impaired psychosocial functioning, such as perceived stigma and lack of autonomy/independence life. All these findings are consistent with literature (Livneh et al., 2001; Baker, 2002; Hosseini et al., 2010; Jacoby et al., 2015); highlighted the perceived poorer quality of life amongst people with epilepsy, and lowered psychosocial well-being and their association with poor seizure control, fear of seizure, perceived anxiety and social life restrictions.

This exploratory study revealed so many important feelings of British people who expressed their negative experiences in living with epilepsy. As an example, negative psychological consequences were not ignorable. This is because it was revealed that British people appeared to feel anxious as a consequence of unpredictable seizures. However, the feeling of anxiousness was not confined to the nature of an epileptic seizure. It was perceived that urinary incontinence was the extra pressure for some of the British people, where they pass urine whilst having a seizure. This could mean that it might be a hard experience for them as they felt ashamed of themselves and anxious afterward. Looking at seizure impacts which had negative effects on British individuals' life, make it an excellent context to explore how and in what way people cope with these issues attached to their seizures. Therefore in order to have a comprehensive view of living with epilepsy, another exploratory study is necessary to

investigate coping strategies applied in the United Kingdom. The next study will explore how and in what way people living with epilepsy cope with their illness.

## **5.8 Study Two**

To date literature has mostly focused on coping strategies from a quantitative perspective (Goldstein et al., 2005; Westerhuis et al., 2011; Bautista et al., 2013), and there is a little work on exploring coping strategies with a qualitative approach, in particular in the field of epilepsy. Since epilepsy is a chronic illness and people may live with the illness for a long period, so there is a possibility to use different coping strategies in different stages of the illness. Therefore, if the coping strategies had been investigated with a quantitative method, for instance, online surveys or other types of questionnaires, such valuable results would have not been achieved.

### **5.8.1 Aim of the Study**

The main objective of this study was to explore how people with epilepsy in the United Kingdom cope with their illness. In particular, this study focused on what helps for coping with seizures and urinary incontinence.

### **5.8.2 Method**

#### ***5.8.2.1 Research Design***

In the current study, a qualitative approach was used. For the purpose of this study the use of in-depth interview as a method of data collection was decided upon.

#### ***5.8.2.2 Participants***

The sample involved ten participants (6 female and 4 male), who were members of ‘The Epilepsy Action’ in the United Kingdom. All these participants met the inclusion criteria for this study; they were required to be aged over 18, and to have British nationality, with a confirmed diagnosis of epilepsy. The British participants’ ages



ranged from 20 to 50 years ( $M=32.90$ ,  $SD= 8.95$ ). The mean years of diagnosis of participants were 14.40 (min =10, max= 20).

### *5.8.2.3 Sampling strategy*

The opportunistic sampling technique was applied. The participants took part on a voluntary basis. The semi-structured interviews took place in an arranged meeting place which was preferred by the participants. Two of the interviews carried out at the participants' home, located in London, since they requested the researcher to have an interview in her home environment and where they could feel comfortable.

### *5.8.2.4 Procedure*

Ethical approval for the second study was obtained from Brunel Psychology Research Ethics Committee (Appendix B). Prior to participating in the interview, participants were requested to sign a consent form (Appendix G) and they were also issued with a participants information sheet (Appendix F). By the end of the interview session, participants were offered the debriefing form to obtain more knowledge related to epilepsy (Appendix G). All participants were informed about the confidentiality of the procedure and that their name will be kept anonymous. They were also told that they are free to leave at any time.

### *5.8.2.5 Interview Schedule*

A semi-structured interview was adopted with participants with epilepsy in the United Kingdom. The interviews took place in the United Kingdom. All interviews lasted between 45 and 60 minutes. All the interview data were digitally recorded. In order to develop rapport between interviewee and interviewer the interview began with brief explanation of the interview, where the participants reassured that the researcher is not going to embarrass anyone with unnecessary questions (Willig, 2001). Also, participants were informed that they were free whenever they wanted to leave the interview session.

The interview schedule consists of open-ended questions (Willig, 2001) (Appendix I). In general, five questions were asked. All of the interview questions were taken from existing literature on coping strategies. The content of the questions were divided into four sections. The first section demographic questions were asked; age, sex, ethnicity, type of epilepsy, and time since diagnosis with epilepsy. The first parts of the questions were broad and generic in a way that the related questions were not sensitive. The second section of the questions were related to coping strategies and participants used in living with their illness, for instances, were asked, ‘Can you tell me how do you cope with your epilepsy’, to see what types of coping strategies can be used amongst Iranian and British participants. Also what was helpful for them in terms of adapting coping strategies? Questions like ‘What do you think is helpful when you are coping with your illness’ was the related question to see what type of support and help participants received in the two different countries. Also responses can be compared in both groups of study to see the pitfalls participants faced in terms of coping with their illness.

The third section of the interview questions dealt with issues linked to urinary incontinence during seizures. Participants were asked whether they were passing urine during the seizure or not. Questions like ‘Are you passing urine during the seizure? If so how do you cope with it?’ clearly asking if any participant was incontinent, how they coped with the problem, in order to see what helps or hinders individuals in terms of passing urine associated with their seizures, the last question was, ‘What do you think is helpful when you are coping with incontinency? These evaluative questions (Spradley, 1979), were helpful as they enabled the researcher to compare the responses across two countries.

## **5.9 Results and Discussion**

### **5.9.1 Data Analysis**

Thematic analysis was used to develop the two main themes, where it emerged themes were able to answer the research question: in what way do people with epilepsy cope with their illness; in particular, with their urinary incontinence. Each main theme description is provided and is interpreted through selected direct quotes from all

participants. Table 3, shows the main themes, each with sub-themes, emerged from the UK interviews. 1) Promoting positive adjustment 2) Confronting with urinary incontinence.

**Table 3 Outlines each theme and corresponding sub-themes for study 2 (UK)**

Themes	Sub-themes
1. Promoting positive adjustment	1.1 Information seeking 1.2 Advanced strategies 1.3 Received support
2. Confronting with urinary incontinence	2.1 Downward positive comparison 2.2 Supportive technique

### **Theme 1: Promoting Positive Adjustment**

Promoting positive adjustment theme emerged amongst British participants, where some of the participants referred to some helpful techniques that might have an impact on how participants cope with epilepsy in a good way. There were some strategies that appeared to help participants to adjust themselves to their chronic condition. This main theme is comprised of three sub-themes: ‘information seeking’, ‘advanced strategies’ and ‘received support’.

#### **Sub-theme 1.1 Information Seeking**

Information seeking appears to have a positive influence on the British participants’ life in order to cope with their illness. Four participants ( 2 male & 2 female) discussed the ways that they could receive help and further pointed out how networking, receiving monthly magazines, searching for illness and epilepsy organisations helped them to obtain the required information and better perception of their circumstance. These participants tend to gather information either from their GPs or other resources in order to adjust well. Here are some examples of the comments that were made by the British participants.

**British Participant:**

The following quote refers to a British man who was enthusiastic to know more about epilepsy. This man believed that his illness was not devastating since he kept searching about his illness. He further reckons that making himself familiar with the illness had positive effects on his perspective where he felt able to go through with his circumstance. It seems that being aware of his condition and seeking information about the epilepsy helped him to adjust himself in a good way. This technique may in turn be considered as a coping strategy where the person tries to search for information about the illness, understand the condition and then once they have enough information they are able to cope well and feel less threatened. He said:

P18.2.50

*I think my epilepsy is not really devastating. At the time it was a big shock for me but gradually I've learnt how to live with it (...). I've started to search about the nature of epilepsy, how it might affect my life and my family and even surrounded people (...), and it seems I've achieved very useful information, I always wanted to be aware of my illness, that has helped me to go through with it (page2, line20-38).*

**British Participant:**

The following quote refers to a woman who was a member of epilepsy organisations not just in the United Kingdom but also she had access to United States' charities via her sister. She kept searching about her illness and it appears she felt better when she received more information about her illness. Receiving monthly magazines about epilepsy appeared to be helpful to her as she could achieve medical information about epilepsy which in turn may help her to adjust herself well to her illness. It seems that information seeking as a coping strategy helped her to perceive positive consequences, as she could understand her illness from others' point of view, and may perceive that how she was coping well with her illness. She mentions:

P15.1.45

*I've been searching a lot (...) I'm a member of charity and I'm getting magazines, these help me to understand my illness from other specialists' perspectives. I also have access to the American Epilepsy Association (...) Receiving information from them helps me to see how well I'm dealing with (...). I can talk to them about the latest medication or any surgery possibilities (...) (page4, line62-74).*

### **Sub-theme 1.2 Advanced Coping Strategies**

This sub-theme emerged amongst British participants. Three participants (2 male & 1 female) in the UK felt that with specific techniques they could cope well and adjust themselves to their illness. Some of them received 'Seizure Response Dogs,' which were named as assistance dogs. These dogs appeared to be trained to detect the auras and warn the person before the actual seizure happen. Others were provided medical bracelet and bed monitor which were helpful in finding emergency numbers and monitoring their seizures, respectively. These strategies may in turn help them to cope with their illness in a possible way. Here are some examples of the comments were made by the British participants.

#### **British Participant:**

The following quote refers to a British man who had severe tonic-clonic seizures. He was provided with an assistant dog, a specific seizure alert dog which he felt was very helpful. He further discussed how the dog was helpful to his parents as well. Before having the trained dog, it seemed that he had problems and was scared of going out. However, since he has been provided with the trained dog, which can detect the auras of his seizure, he has felt safe, satisfied with life and feels that he can go out easily. He further perceives a feeling safety because when he has been out and he has developed a seizure his dog could detect his seizure, the dog warned him before he was about to develop a seizure and so then he has been taken to the nearest safe place. He felt the dog has changed his life, as it appears that he attained his independent life again and because of this it seems he could cope and adjust himself well to his illness.

P 16.2.30

*I used to have bad seizures (...). Now with dog, I can even go out, I'm happy. He starts barking, I can notice that something is going to happen, like if I have my food, I stop it just in case of choking (...). He has been very helpful for my parents, they could notice that I'm going to seizure, and they could take me to the safest place (page4, line50-69).*

### **British Participant:**

The next quote refers to a British man who felt satisfied in terms of living with his illness. He was given a medical bracelet which helped him in dialling emergency numbers during his worst situations. The medical bracelet appeared to be helpful for him as he never felt stressed about developing a seizure. He was also provided with a bed monitor, which will start to shake if a seizure happens in bed. It appeared that with such strategies and facilities he could cope well as he felt fortunate in terms of being able to deal with his illness.

*P13.2.20*

*I think I'm quite fortunate in many aspects because I was given bracelet; it's a little medical bracelet that you can find emergency numbers here, like my dad, my girlfriend (...). I got it from charity since fits gets worse and if I get fit, I can call my dad (...). I also have got a bed monitor which basically can detect if your bed starts shaking. It's called epileptics seizure monitor (page4, line35-101).*

### **Sub-theme 1.3 Received Supports**

In this study, the majority of the British participants felt they received satisfactory support from various related organisations and also financial help from the NHS. Four participants (3 female, 1 male), reported that this support was sufficient for them to adjust themselves to their illness in a good way. They felt how receiving free NHS medication, where they did not need to pay for their medicines was financially helpful. This support may in turn help them to manage their illness in the best possible way. Here are some examples of the comments which were made by British participants.

**British Participant:**

The following quote refers to a British woman who received great help from her university. She was provided with sufficient care as she was known by the University to have epilepsy. The support she received from her university led her to perceive positive consequences as she did not feel discriminated against, indeed she felt empowered to cope with her illness instead.

P17.1.25

*I've applied for DSA disability support allowance (...) If you miss lectures, you have got reason why, and you get automatic allowance to record any lectures (...).They have to give you your hand-outs in advance (...) I get extended library loans (page5, line105-120).*

**British Participant:**

Another quote presented below refers to a British woman who was receiving free medication from the NHS. It appears that not having to pay for medication was a great help to her by not having the financial burden of medical costs through the support she received from the NHS. In turn this was a helpful factor and she felt enabled to adjust herself well to her illness.

P.11.1.35

*I've been receiving free medicines since I can't remember really, but anyway it's a long time, and what happen is, when I get my prescription then head off to the Boots and pack up everything(laugh). But yeah, with me I'm so thankful that I don't need to pay, otherwise, it would be disaster for me (page6, line121-128)*

**Theme 2: Confronting with Urinary Incontinence**

Passing urine has been one of the most common issues amongst people with epilepsy a factor highlighted in the first study, where a number of individuals pointed out their negative experiences relating to the passing of urine, which appeared to be associated with anxiety, shame and embarrassment. In the current study, this issue was considered

and accounted for. It was therefore included as one of the interview questions, and people with epilepsy were asked if they might pass urine during seizures and if so how do they cope.

Responses suggest participants tend to compare themselves with others who have a worse situation than their own and it appeared this helped them feel better in terms of adjusting themselves to their own illness. They explained how well they felt in comparison to these individuals. Others were satisfied using pads as a coping strategy with incontinence. So this theme comprised of two sub-themes: 'downward positive comparison' and 'supportive technique'.

### **Sub-theme 2.1 Downward Positive Comparisons**

People living with epilepsy, it appears like to compare themselves with others to see how well they are doing in comparison and this is a way they are able to gather information in order to evaluate themselves. This type of self-evaluation presumably enables the individuals to feel safe and perceive positive consequences, for instance, by feeling better in comparison to others who are less fortunate. Thus developing a downward positive comparison which may be a coping mechanism enabling the individuals to feel better in comparison to their less fortunate target. This could help individuals with epilepsy to adjust well to their illness. For instance, comparison to someone with an overactive bladder, a person with a urinary tract infection or the elderly population are all examples of targets which led the participants to feel better in a way that at least they are not continuously incontinent and only experience the passing of urine during their seizures. It is interest to note that upward comparison, contrast, identification dimensions and downward identification dimension did not emerge as a coping strategy in this study.

Of the four participants who reported they experienced incontinence, three of them (2 female & 1 male), felt better in terms of dealing with incontinence when they compared themselves to those who lived in worse conditions, because they felt dissimilar. This might be related to their individual circumstances, in a way that people tend to evaluate and assess their own health status in comparison to others, and perceive positive effects. For instance, if the target is less fortunate than the



individuals forming the comparisons, then the individuals are empowered because they can see themselves more likely to have good health in comparison to the target group.

Here are some examples of the comments that were made in the United Kingdom to demonstrate positive downward comparison.

**British Participant:**

The following quote refers to a woman whose condition is such that she urinated when she had a seizure. She described her issue and said that passing urine happens to her at night time only, whereas her friend had the same problem but also urinated in the day time. Although she shared the same problem which is similar to her friend, she was in a situation which was comparatively better than her friend's. It also seems the action of comparing herself with her friend had a positive influence on her, which led her to adjust herself to her issue. For instance, she was thankful for having this problem only at night time, because she could conceal it from others and perhaps in this case she felt less ashamed and embarrassed. In other words, she compared herself to the worse-off case, and felt dissimilar. So she perceived positive consequences, in a way that she could adjust well.

P11.1.35

*A friend of mine wet herself but in a day time! I know how awful it is (...)But I keep saying, it's good though (...)I always get it midnight(...)because at least no one can notice; specially my kids.(...) I'd rather to change my bed sheets, than make myself wet in public; when I see her(...) I find myself doing really great (page7, line 148-158).*

**British Participant:**

This quote refers to a man who felt better in comparison to others with different types of bladder problem. For instance, he compared himself to people who don't just pass urine during seizure alone, but also throughout the whole day. It appears that feeling positive whilst comparing his situation to others in a worse condition than his own and

with bladder infections, enabled this man to perceive positive consequences, and he was thankful for it.

P12.2.31

*I do believe that there's always someone worse than me, like somebody with overactive bladder, or with any other types of bladder infections that I know how would it be horrible (...), they might be leaking for whole day. I've been very lucky indeed. I can count my blessing when I'm looking at those people, and feel like... like 'Ok' I'm doing alright (page9,line229-237).*

### **Sub-theme 2.2 Supportive Technique**

This sub-theme refers to a strategy reported in this study as a coping mechanism for incontinence. One of the female participants felt satisfied receiving free pads from the NHS. Using the pads was a technique that turned out to be helpful, in terms of coping for the participant. Here is the comment made by this British participant.

#### **British Participant:**

The following quote expresses a woman's feeling about receiving satisfactory support from the NHS because she received free pads. It appears passing urine had a negative impact on her because she had difficulties prior to receiving her pads; she used to experience leakages in public and felt scared of being out and having a seizure, which could result in her passing urine. However since she has been provided with free pads from the NHS, she has found the situation has improved because she has been given a resource to deal with any possible future leaks. She felt much better with this support and it seems since she has been receiving the pads she has been able to socialise more and she has enjoyed recreational activities, such as attending parties without a worry about her incontinence. In other words, she used pads as a technique to cope with her incontinence. There was therefore perceived satisfaction as a result of the support received from the NHS. She stated:

P20.1.28

*I've got pads, which is for free. (...) now I do feel much better. I used to wet myself in public during the fits, it was horrible (...) I used to go out rarely, I scared of getting fit. But since I've got these pads, I do have more life. At least*

*now when I'm off to party, or clubbing, I can have pads on. Personally I found it really helpful, because it keeps me active, no limitation for me anymore (page6, line118-130).*

## **Discussion**

The aim of the current study was to explore coping strategies amongst people with epilepsy in the UK. Specifically, the current study aimed to answer the research questions ‘in what ways do people in the United Kingdom cope with epilepsy?’, ‘how do they cope with their incontinency?’ This has been achieved through the development of the themes from interviews with participants in the United Kingdom. The comments by each participant were influenced by their own experiences. To the best of the researcher’s knowledge, these expressions had not been previously reported to describe the experience of living with epilepsy; therefore, this study is a first attempt to explore how people experience their lives’ with epilepsy.

*Promoting positive adjustment* was the first main theme which emerged from the British sample. It covered ‘information seeking’, ‘advanced coping strategies’ and ‘received support’. Information seeking appears to refer to practical techniques that British people were eager to use in adjusting to their chronic condition. This supports the problem-focused coping theory by Folkman and Lazarus (1980); individuals actively engage in obtaining information to solve the problem. The authors stated that if the stressor is perceived as controllable, then problem-focused form of coping increase, such as plan a solution or taking an action (Piazzini et al., 2007). This could mean that British people perceived the illness as a less threatening subject, which led them to have a better understanding of their illness as a result (Kemp et al., 1999; Piazzini et al., 2007). These findings also support previous research by Livneh et al. (2001), where information seeking was conceptualized as a task-oriented strategy amongst people with epilepsy. This in turn, helps to plan a solution and find required medical information for patients. In an extension of the above study, problem-focused coping has been considered as an engagement coping strategy (Roth & Cohen, 1986). In this regard, Livneh and colleagues (2001), suggested information seeking as a problem-focused coping strategy, providing individuals with the context in which they

can actively engage in investigating their stressful condition. This was in line with a recent study by Bautista et al. (2013), which highlighted engagement as a type of coping strategy for epilepsy patients which involves patients actively managing their medical condition. Earlier coping strategies and their association with psychological well-being were examined (Krakow et al., 1999; Oosterhuis, 1999; Goldstein et al., 2005). The authors highlighted the problem-focused coping strategies as the most helpful strategies in psychosocial adaptation amongst patients with intractable epilepsy. However worse psychological well-being was reported amongst those who were engaged in maladaptive coping strategies (Goldstein et al., 2005). Krakow and colleagues further reported high levels of depression amongst those patients who used denial as a coping strategy, which led to poorer psychosocial adaptation to epilepsy (1999). It can be argued that British people with epilepsy appeared to perceive their illness as a controllable event, as they were more likely to use the problem-focused coping strategies. This is because they were eager to actively manage their illness through activities such as seeking medical information about epilepsy, being members of organisations, actively engaging in charity conferences and keeping themselves updated with reading monthly magazines on epilepsy. All of these attempts appeared to assist them in perceiving the illness as a less threatening event and more controllable and this would help them to have a better psychological well-being (Goldstein et al., 2005; Westerhuis et al., 2011).

Coping strategies in this study were not confined to the above mentioned techniques. This could mean that British people with epilepsy receive more support and unique methods of support beyond these common coping strategies and where the support offered has been successful leading the individuals to feel better adjusted to their epilepsy.

Advanced coping strategies and received support as sub-themes are effective coping mechanisms because they were associated with positive outcomes which enabled participants to feel they had received the required support from a charitable organisation or from the NHS. Support offered by the NHS referred to in the literature, such as free medication and free pads as a form of containment device, all helped patients in a way that did not involve a financial burden to them personally. This all indicates that individuals with epilepsy in the United Kingdom feel satisfied in terms

of not having to incur medication costs and this appeared to help them by not having to worry about finding funds for their medication or medical supplies. Kerr et al. (2011), confirms that adequate medical support in the United Kingdom amongst people with epilepsy provides a major reduction in the negative impact of this chronic illness.

This study also revealed that seizure alert dogs or assistance dogs have been known as potential helpful resources to help British people adjust to their illness. To date it has been well documented that assistance dogs have a great psychological impact on people with disability (Crowe et al., 2014); physical impairments (Fairman & Huebner, 2001), and Parkinson's disease (Earles, 1998). Recently, these dogs have provided practical benefits for people with epilepsy (Dalziel et al., 2003). It is known that seizure alert dogs can detect auras, and also can help people with complex partial seizures (Dalziel et al., 2003). More interestingly, seizure alert dogs are not only beneficial to warn the handler but also they play a substantial role in reducing the seizure frequency amongst patients with tonic-clonic seizures (Strong et al., 2002). It was suggested that trained dogs can recognise particular changes prior to seizure onset, where they can give an explicit signal which in turn enables the dog to warn the person (Strong et al., 2002). These facilities may help British people to feel confident enough to be more socially active and less threatened by the unpredictability of their seizures, as they are able to prepare for the developing seizure in advance. In addition these findings might have implications for clinical intervention in relation to decreasing seizure frequency and seizure management for people with epilepsy (Goldstein et al., 2005; Westerhuis et al., 2011). This technique would be of interest to care providers as the animals are able to provide an alert that something is going to happen to the person with epilepsy. In addition since trained assistance dogs can detect an aura, stress is reduced because the risk of an unpredictable seizure is minimised and this could mean onset is negated, as reported by Strong et al. (2002). All of these supportive techniques may help British people with epilepsy perceive their illness as a less threatening subject.

This study showed that some of the participants discussed their views about how they deal with their incontinence; if they pass urine during the seizure and how they adjust themselves to their incontinence. Downward positive comparison appeared to be a

coping mechanism for British people who pass urine whilst having a seizure. This could mean they were engaged in coping with their incontinence by comparison technique with others who are less fortunate. This supports the Identification/Contrast model (Buunk & Ybema, 1997); signifying that British people felt better adjusted after comparison to their less fortunate target, as they felt their situation was dissimilar to that individual. The authors proposed that positive social comparison is related to positive adjustment and perceived positive consequences as a result. In the current study, the downward positive comparison appeared to build upon the work of Wills (1981), indicating that threat always leads to downward comparison, that is, the comparison with less fortunate targets enables the individual to learn how to cope in a positive way. Based on this theory, when individuals are under threat in order to enhance their self-esteem they prefer to compare themselves with others who are worse-off. This theory was later commented on by Wood et al. (1985), looking at different social comparison aspects in adjustment to breast cancer. The authors revealed the majority of women with breast cancer applied downward positive comparison to cope effectively and to enhance their self-esteem. The suggested findings of the downward positive comparison as a sub-theme highlighted the British participants aimed for a comparison with targets who are worse-off (Wills, 1981) and for ego enhancement (Stanton et al., 1999). In addition, the findings may support the Cognitive Adaptation Theory (Taylor, 1983), emphasised on self-enhancement as a process of adjustment to the threatening event. This is important to this study as Taylor (1983), believed that self-enhancement is achievable with downward positive comparison. Applying this to epilepsy, British people who had urinary incontinence were engaged in positive comparison to others who are worse-off for self-enhancement. It is known that the interpretation of social comparison dimensions are used as coping mechanisms in order to adjust to chronic illnesses, for instance, Meniere's disease (Dibb & Yardley, 2006), women with breast cancer (Bogart & Helgeson, 2000), (Van der Zee et al., 2000), amongst cancer patients and people with spinal cord injury (Dibb et al., 2013); they all suggest that downward positive comparison has the potential to inspire people in the context of living with chronic illness. Yet no study has highlighted positive social comparison (downward), as a coping strategy in living with epilepsy. The suggestive findings appear to confirm results in the previous study by Dibb and Yardley (2006), where they investigated the

social comparison influences in people with Meniere's disease. It was recognised that social comparison was associated with adjustment to chronic illness; the more positive social comparison was applied the higher the level of adjustment was perceived (Dibb & Yardley, 2006). It can be argued that feeling better in comparison to someone who experiences leakage during the day, led British individuals to perceive a better understanding of their own circumstances; in a way they evaluate themselves to see how well they are doing, and 'count their blessing' that at least they just passed urine whilst having a seizure. In addition Bogart and Helgeson (2000), found support for downward positive comparison as a coping strategy amongst women with breast cancer. They reported that patients felt better adjusted when they compared themselves to those in worse circumstances. The positive effect of social comparison (downward) has been evident in other neurological settings. Dilorenzo et al. (2008) reported downward positive comparison as an adaptive coping strategy amongst patients with Multiple sclerosis. The authors stated that this type of comparison could assist patients to have a positive perspective of themselves.

The importance of positive social comparison (downward), in the adjustment process for coping with epilepsy, in particular with urinary incontinence, has an implication for these new approaches. This is because individuals can still feel better by comparison to others who are less fortunate, and they perceive a better understanding of their own lives. This is important to determine the coping strategy as a way of adjusting in order to cope with urinary incontinence in the samples from the United Kingdom.

However there has not been enough literature to support this finding, hence this research provides a contribution to the growing body of knowledge, in that it will help health professionals consider the link between urinary incontinence in epilepsy, psychosocial adaptation and the various coping strategies people may use.

It is possible the positive feeling participants experiencing incontinence felt in comparison to someone less fortunate may contribute to a positive effect on their perception of quality of life, based on the Identification/Contrast model (Buunk & Ybema, 1997), participants may have evaluated their experiences with others who are worse-off for example people with an overactive bladder, the elderly population or

other patients who experience incontinence during the day, which in turn led to positive effects being perceived.

### **5.10 Conclusion**

It can be concluded the British participants appeared to perceive epilepsy as a controllable event as they were more likely to use problem-focused coping strategies, such as information seeking. British people were more likely to manage external demands since they appeared to be able to find an appropriate solution through perceiving their illness as less of a potential threat to their lives. This positive perception of their illness may be associated with perceiving a better understanding of their quality of life.

It should be acknowledged the principle aim of this thesis is to examine the role of social comparison on the perception of quality of life amongst people living with epilepsy in the United Kingdom and Iran. However to achieve this goal prior to doing analysis; the researcher developed the exploratory studies in the United Kingdom and Iran, on a separate basis, to see how people experience their life with epilepsy, whether they are even socially compare themselves to others. To do this, the next chapter will explore the qualitative analysis of the Iranian sample.



## **CHAPTET SIX: THE QUALITATIVE ANALYSIS OF IRANIAN SAMPLE**

### **6.1 Introduction**

There are considerable differences in the healthcare system, epidemiology and related research on epilepsy between the United Kingdom and Iran. Most research into epilepsy has been conducted in Western cultures (Baker, 2002); so far there has been limited published research investigating epilepsy in Iran. Social differences should not be neglected in investigating epilepsy. This is because illness patterns and the way in which patients are receiving treatment may vary within the different social contexts.

This study is the first attempt in Iran to explore the experience of individuals living with epilepsy from a different perspective. It is important to conduct this research in the Middle East in order to identify the differences or similarities to improve the overall quality of life for people living with epilepsy in Iran.

This chapter covers two qualitative studies carried out in Iran. The first study has a foundation on investigating the life experiences of people living with epilepsy. The result of the first study has led to develop the second study, focusing on the exploration of coping strategies of seizure impact amongst people living with epilepsy in Iran. The aim, method, results and discussion of each study will be discussed on a separate basis.

### **6.2. Study One**

#### **6.2.1 Aim of the Study**

The main objective of this study was to explore how people with epilepsy experience their life in Iran.

#### **6.2.2 Method**

##### **6.2.2.1 *Research Design***

In the current study, a qualitative approach was used. For the purpose of this study it was decided to use of in-depth interview as a method of data collection.

### *6.2.2.2 Participants*

The sample involved ten participants (4 male and 6 female), who were members of the ‘Iranian Epilepsy Society’ in Iran. All of these participants met the inclusion criteria for this study; they were required to be aged over 18 years, and have Iranian nationality, with a confirmed diagnosis of epilepsy. The Iranian participants’ ages ranged from 29 to 50 years ( $M = 35.10$ ,  $SD = 7.15$ ). The mean years of diagnosis for the participants was 15.60 (min = 6, max = 22) years.

### *6.2.2.3 Sampling Strategy*

The opportunistic sampling technique was applied. The participants took part on a voluntary basis. The semi-structured interviews with the Iranian participants took place at the neurological hospital in Tabriz, in an out-patient clinic. The researcher was supervised at all times by specialists to prevent any misunderstanding between interviewee and the interviewer; however each volunteer after agreeing to participate in the study, was taken to a separate room for the purpose of privacy and the provision of a more comfortable environment for them.

However two of the interviews were conducted in the participants’ homes, as they were living out of the city, in small towns where they were quite a distance from the hospital, and so, it was their preference to be interviewed at home.

### *6.2.2.4 Procedure*

Ethical approval for the study was obtained from Brunel Psychology Research Ethics Committee (Appendix A). Permission for the Iranian study was obtained from the head of East Azerbaijan Epilepsy Association which is located in Tabriz at the neurological hospital (Appendix C).

Prior to participating in the interview, interviewees were requested to sign a consent form (Appendix E), and they were also issued with a participant’s information sheet (Appendix F). By the end of the interview session, participants were offered the

debriefing form to obtain more knowledge related to epilepsy (Appendix E). All participants were informed about the confidentiality of the procedure and that their names will remain anonymous. They were also told they were free to leave at any time.

#### *6.2.2.4.1 Interview Schedule*

A semi-structured interview was conducted with individuals living with epilepsy. Since the aim was to achieve insights into the lives of individuals, the semi-structured interview approach contained open-ended questions, (Willig, 2008), (Appendix H). Each interview started with a general overview of the process, which helped in making the interviewees feel comfortable and also to develop a rapport with the interviewer (Willig, 2008). Given that Iranian participants appeared to be conservative, the interview durations were less than 45 minutes. All of the data gathered from the interviews was digitally recorded.

The first few questions were mostly aimed at obtaining demographic information about the participants such as age, gender, ethnicity, type of epilepsy, and time since diagnosis of epilepsy. Once the demographic information was obtained, the following questions were asked: ‘What your feeling was when you were first diagnosed with epilepsy?’ ‘How long have you had epilepsy?’ ‘What is your experience of having a seizure?’ ‘Can you expand on that?’ ‘How do you feel in yourself?’ ‘How do you feel after a seizure?’ ‘How often do you have seizures?’ ‘Do you take your medicine regularly?’ ‘What is it like living with epilepsy?’ ‘Do you think epilepsy changed your life since your diagnosis?’ ‘Are there any other things that are important to you in living with epilepsy?’ ‘What bothers you about living with epilepsy?’ ‘How do you evaluate yourself in interacting socially?’ and ‘How freely can you discuss your illness with family and friends, and others?’ These descriptive questions were designed to gain general information from the participants (Spradley, 1979). No direct questions and leading questions about alcohol consumption or social comparison were asked during the interview sessions.

## 6.3 Results and Discussion

### 6.3.1 Data Analysis

Each main theme description is provided with illustrations through direct quotes from participants. Five main themes were identified. They are: upward negative comparison, seizure impact, limited participation in life, perceived triggers and negative consequences of living with epilepsy which is presented in Table 4. The following themes were extracted from the data which will be presented below:

**Table 4 Outlines of each theme and corresponding sub-themes for study 1 (Iran)**

Themes	Sub-themes
1. Upward negative comparison	
2. Seizure impact	2.1 Fear 2.2 Anxiety 2.3 Urinary incontinence
3. Limited participation in life	3.1 Perception of stigma 3.2 Loss of independence
4. Perceived triggers	4.1 Sleep deprivation
5. Negative consequences of living with epilepsy	5.1 Experience of employment 5.2 Overprotectiveness 5.3 Insufficient financial support

#### **Theme 1: Upward negative comparison**

There are important factors that may have an influence on the life experiences amongst people with epilepsy. With this in mind, when the Iranian participants explained how they experience their life with epilepsy, the majority of them based their feelings on how they were comparing themselves to other people in their lives without epilepsy. Therefore upward negative comparison themes were developed as the first main theme in this study.

Six participants in Iran perceived that they did socially compare themselves with fortunate others. This type of comparison refers to comparison with someone negatively who is perceived to be in better circumstances. These participants were engaged in negative upward social comparison. 'Jealousy,' was a feeling perceived by Iranian participants, which again indicates their negative upward comparison.

Repeated instances of this were found during the interview. Explanations of this comparison were typically situated in the context of friendships. In the current study, the upward negative comparison theme appeared to emerge as one of the most common types of social comparisons, specifically amongst those participants who were diagnosed with epilepsy later in life. It appears late onset in epilepsy leads people to feel comparative to others in a negative way. This might be related to encountering unclear challenges which participants were unused to having before their lives with epilepsy. These kinds of challenges might lead participants to feel down and embarrassed. Here is an example of a comment made by a participant in Iran:

**Iranian Participant:**

In the following quote, an Iranian male, explained how taking a shower appeared to be problematic for him, as he was scared of having a seizure in the shower. This feeling of panic may lead him to avoid taking showers on a regular basis. Being unable to take a shower or staying under the hot water is built upon an imagined feeling of suffocating in the bath. Such kinds of feelings led him to compare himself to those of his colleagues who could take a shower every day. Therefore feelings of jealousy developed between him and his colleagues, and so he felt inferior in comparison to them. In addition since he was diagnosed with epilepsy later in his life (22 years); it appeared that it was difficult for him to live with epilepsy, as every single challenge was new for him. Even the simple task of taking a shower, he had never imagined that one day he might be scared of taking a shower. It seems that the diagnosis of epilepsy at a later age in life, led him to experience a challenging lifestyle which may have resulted in the build-up of jealous feelings.

P 9.2.31:

*When I want to take a shower I can't do it. I feel like hot water is suffocating me! When I'm going to the office and I see my colleagues, I do get jealous, I think they took their shower but I can't take one every day. This kind of feeling makes me to feel inferior (...). I was never jealous before as I hadn't had epilepsy in my life, and since I got it, everything has changed, even taking shower (...)* (page4, line72-82).

## **Theme 2: Seizure impact**

Seizure impact emerged as the second main theme because there were numerous factors that influenced seizures amongst the Iranian participants which have affected their lives seriously, namely: fear, anxiety and urinary incontinence. In the current study these factors have been developed as sub-themes which will be demonstrated in some examples of comments which made by the Iranian participants.

### **Sub-theme 2.1: Fear**

In the interviews four of the participants expressed a feeling of fear, they recognised this particularly as a fear and concern of having their next seizure and possibly in the presence of others. This is because they did not know when they would develop their next seizure. They explained how they were scared of developing a seizure directly after experiencing one and having just recovered from the previous one. Here is an example of the quotes which were made by the participant to indicate the fears carried in their mind:

#### **Iranian Participant:**

The following quote refers to an Iranian woman who had a fear of having a seizure at night and this fear was serious for her. She suffered with nocturnal seizures which made her feel worried in the morning. This might lead her to feel threatened every morning. She also expressed her fear of death, which might occur due to a seizure. It appears that she was scared of seizure recurrence, which led her to feel shame and embarrassment as a consequence.

P3.1.35:

*Most of the time, I have a seizure at midnight. Such a shame, every night I've this constant fear in my mind that I might never wake up again in the morning (...). It's unbelievable that every day when you wake up, you have a kind of thought that, 'when I'm gonna develop the next seizure?' I feel ashamed of myself. (page3, line 37-46).*

### **Sub-theme 2.2: Anxiety**

During the study, it was perceived that half of the participants in Iran felt anxious as a result of their seizures. Especially as some of them experienced anxiety due to a consequence of the unpredictable nature of their seizures, which may happen in public because they did not know when or where they were going to have a seizure. The symptoms of feeling anxious amongst the Iranian participants was based upon their, 'worrying thoughts,' and 'feeling scared that something bad is going to happen.' It is possible that amongst people diagnosed with epilepsy, psychological distress might be associated to the illness, or epilepsy itself might lead them to feel anxious. Here is an example of the quotes made by an Iranian participant to indicate a feeling of anxiety.

#### **Iranian Participant:**

The following quote is from an Iranian female participant. She expressed being scared or anxious of being in public places in case she had a seizure. This kind of anxiety could be linked to seizure recurrence, and the possible embarrassment she may face in front of others. This could mean that anxiety and fear overlapped each other. It can be said that she felt anxious as a result of seizure recurrence, and it seems that experiencing such fear elevated a feeling of anxiety afterwards. In addition, she suffered with urinary incontinence.

From her responses during the survey it can be inferred that the fear of having a seizure and wetting herself makes her highly anxious, because she would be embarrassed in public. It also seems that the unpredictable nature of her seizures made her feel distressed and uncomfortable. It appears that worrying thoughts and a feeling that something bad was going to happen are associated with feeling of anxiety. She discussed her view related to these feelings which were constantly on her mind.

P7.1.30:

*I can't stand being in social places. Being in such places makes me feel more anxious (...). When I'm going to a party, I feel stressed as I don't know when a seizure will come; especially in terms of passing urine, it's just horrible. I feel worried when I think of wetting myself in public (...). In social gatherings I feel something really bad is going to happen! (...) because I'm anxious about having a seizure (page5, line108-122)*

### **Sub-theme 2.3: Urinary incontinence**

During this study, there was an issue which appeared to be perceived amongst several of the participants. Half of the participants talked about passing urine during their seizures. It has been shown that urinary incontinence may have a psychological and social impact on peoples' lives (reviewed in Chapter 1). Perhaps the psychological stress of dealing with incontinence is considered as one of the main reasons for experiencing anxiety amongst the Iranians. It can be said that some of those participants who were passing urine during their seizures appeared to feel anxious in terms of wetting themselves because of the embarrassment associated with it. Here is an example of a comment made by an Iranian participant:

#### **Iranian Participant:**

A male Iranian participant suffering with urinary incontinence, explained how passing urine during his seizures was embarrassing for him. He often felt ashamed of himself. It appeared that he did try his best to understand why he was passing urine; he tried to keep his bladder empty in the hope of not passing urine during a seizure; however this did not work for him. Passing urine made him feel embarrassed because he is married; given that he is 31 years old, and old enough to not pass urine. He felt ashamed of himself because he often found himself wet in morning.

P8.2.31:

*The most terrible thing is I wet myself during a seizure which is quite embarrassing (...). I did try to go to the toilet every hour, but still it doesn't relate to my bladder because sometimes I feel that I don't need to go to the*



*toilet, but I develop a seizure and then I might find myself wet again. I'm married, (...). As a man I do feel ashamed of myself, and I am tired of finding myself wet (page5, line97-109).*

### **Theme 3: Limited participation in life**

Epilepsy may affect an individual's life and it does so in different ways. This theme which was perceived in the dataset discusses numerous limitations the Iranian participants may face in their daily life activities. Factors such as, perception of stigma and loss of independence were considered as sub-themes. These factors were seen as obstacles which restricted participants in their daily life activities.

#### **Sub-theme 3.1: Perception of stigma**

Three Iranian participants admitted they had experienced unpleasant attitudes from people in public. The current sub-theme refers to participants' interaction with others and how they have been treated negatively by other people without epilepsy in Iranian society. The general public's reactions appeared to affect the participants in Iran irrespective of whether they chose to tell people about their illness, or preferred to conceal their condition because of the stigma attached to epilepsy itself which often leads to discrimination. This sub-theme may suggest that there is a high level of perceived stigma towards epilepsy in Iran, because it may be considered as a 'cultural taboo'. Below is an example of a comment made by an Iranian participant:

#### **Iranian Participant:**

This Iranian female participant described how her seizures affected her friendship with a close friend. She described the embarrassment and shame she had to face due to her biting her tongue during a seizure. It seems that it was very difficult for her to overcome this shame and embarrassment that she had to face. Her friend's attitude annoyed her especially because her friend believed that epilepsy was contagious and she might get it. This belief annoyed the participant as it was not true. Furthermore her friend believed that people with epilepsy are disabled. These factors made her feel

embarrassed. It can be understood that there is lack of awareness about epilepsy in Iran, which in turn leads people to misjudge the illness, either by assuming the illness is a viral disease or considering the illness as a disability. Although she was with her friend, she was not in a friendly environment, therefore she felt humiliated and degraded.

It appears that she was faced with peer pressure due to her illness and felt stigmatised after being told that epilepsy is a form of disability. As a result, she did not feel comfortable in front of her friend, and perceived negative feelings towards her. Biting of the tongue is one of the common occurrences during an epileptic attack (reviewed in Chapter 1); however, it seems biting the tongue for a person with epilepsy in Iran, might be an unusual experience as the friend of this participant didn't understand what could have caused the blood on her friend's jacket. Her response to her in turn led the participant to feel degraded:

P1.1.29:

*Once I had a seizure when I was in my friend's house, suddenly she came and said, 'what's that blood on your jacket?' I didn't know I had, had a seizure, I became aggressive and I felt ashamed. I looked in the mirror and found blood on my face! (...) I hate biting my tongue (...). My friend never talked to me as she thought that epilepsy is contagious (...) and epileptics can't work; she believes that we're 'disabled' (page4, line71-86)*

### **Sub-theme 3.2: Loss of independence**

One of the reported concerns from the Iranian participants was not being able to lead a completely independent life, due to the effects of having a seizure. Amongst the participants, four said they were not able to live a satisfactory independent life. Hence loss of independence as a sub-theme emerged. Iranian participants commented on having restrictions to ordinary, everyday life experiences, (e.g. shopping or taking a shower), which resulted in a restriction to their independence. Here is an example of the comments which were made in Iran to express the difficulties people with epilepsy face due to their dependency on others:

### **Iranian Participant:**

In the following quote a female Iranian participant explained how challenging it is living with epilepsy. The restriction on her independence affects her daily activities and makes her feel as if she is, 'living in a cage'. It appears that she is dependent on her family even in her ordinary day-to-day life activities, (e.g. shopping). She is afraid of going out by herself just in case she develops a seizure. This fear makes her feel as if she has to depend on her family.

Being dependent on others makes her feel frustrated and embarrassed, and at the same time, makes her opt out of practical activities, such as shopping. As a consequence, it leads her to imagine herself as a little injured bird which is unable to fly. For her, a bird symbolises an independent creature and she wishes to have her own independence.

P4.1.38:

*Living with epilepsy for me is "like living inside a cage," as I am not independent. I always depend on my husband; even depend on my little son. I can't go shopping; I'm scared of having a seizure (...). Always someone should be with me. Living with epilepsy is like living in a small cage, I feel like an injured bird trapped inside (page4, line71-78).*

### **Theme 4: Perceived trigger**

During the interviews with Iranian participants, they placed an emphasis on insufficient sleep that may cause them to develop more seizures (reviewed in Chapter 1). This main theme referred to as, 'perceived trigger,' comprised of the following sub-theme: 'sleep deprivation'.

#### **Sub-theme 4.1: Sleep deprivation**

This sub-theme was developed from discussions about experiencing an inadequate amount of sleep, which could be a trigger for seizures. It appears that sleep is a major problem for some of the Iranian participants. They often make a link between seizure

frequency and having insufficient amounts of sleep. Three participants in Iran explained how an inadequate amount of sleep is a major issue for them to tackle. Sleep deprivation is important since the participants feel that it can make seizures more likely to occur. Some of the participants explained how sleep deprivation works as a trigger for seizure recurrence since it makes them have a seizure the next day. In addition the side-effects of medication are reported as a trigger which leads participants to experience insomnia in some cases. Staying awake for some consecutive days was perceived to be a cause in the development of more seizures. Here is an example which was made by a participant in Iran:

### **Iranian Participant:**

A female Iranian participant spoke about sleep deprivation. Since she changed her medication, it appears she has experienced some side-effects, such as insomnia. She explained this is because she had experienced 3 consecutive days without sleep. It appears the side-effects from the medication had a negative impact on her sleep pattern, as she was awake for three days and without being able to have enough sleep within those three days, she perceived the sleep deprivation as a trigger to her seizure onset.

P6.1.30:

*I think because of my medication gives me side-effects. I can be awake for 3 days, nearly 72 hours and then I develop seizure within three days as I don't have enough sleep. I was told to avoid caffeine for at least 5 hours before going to sleep but it didn't work. I also avoid having too heavy foods at night just in case that causes me insomnia, but it's not working (page3.line33-45).*

### **Theme5: Negative consequences of living with epilepsy**

Epilepsy and the long-lasting nature of the illness may lead individuals to have demanding times in their life. Some participants have encountered some obstacles, such as losing their jobs or others might feel overprotected by their families. Financial

problems are one of the most common reported issues for people with epilepsy on a limited income in Iran. This however, might be specific to the government's legislation in the different countries, that is, whether they offer support towards the costs of medication or not. Negative consequences of living with epilepsy as a fifth main theme is comprised of three sub-themes: 'experience of employment', 'overprotectiveness', and 'insufficient financial support'.

### **Sub-theme 5.1: Experience of employment**

Half of the Iranian participants felt they faced challenges regarding their employment status. They expressed their negative experiences whilst being employed which has been considered as a barrier in their life. Some of them felt they perceived discrimination which led them to lose their jobs. Trying to hide the illness was often the case for some participants, seeing that some of them discussed their preference to keep their illness concealed. In other words, living with epilepsy appears to affect individuals' employment cycle in Iran. Here is an example of a comment made by an Iranian participant:

#### **Iranian Participant:**

The following quote highlights how an Iranian man, who had been working for many years, lost his job when his epilepsy was revealed. It could be argued that due to his perceived discrimination, he chose to conceal his illness and did not tell his employer that he had epilepsy. Perhaps the shame also associated with epilepsy, led him to hide his illness. He believed that having a seizure in the work place, led him to lose his livelihood which severely affected his career as since then he struggled to find an appropriate job for himself. This negative experience of his employment led him to perceive negative consequences associated with his illness, such as shame and embarrassment.

P5.2.50:

*I used to work for a company (...). I had never told them before about my epilepsy. Once I had a seizure in the office (...), everyone noticed. It was very embarrassing (...). One month later, I received a letter which was my termination of contract. They didn't keep me as an employee anymore (...). Then for me it took a long time to get another job where I'm not employee anymore (page5, line67-77).*

### **Sub-theme 5.2: Overprotectiveness**

Four of the Iranian participants felt overprotected by their families, in particular by their parents. This may be based on the individuals being diagnosed with their illness later in life, which may in turn lead people to experience new challenges in their lives. When a person is diagnosed with epilepsy, it is natural for parents to be worried about their child's life, and it is obvious that parents would like to protect them in every aspect. But it appears that being too protective is not a good feeling for some individuals with epilepsy, and occasionally it might be considered as restrictive or a barrier to life with a chronic illness.

Some of the participants perceived they were, 'Feeling like a 'kid.' This appears to have had a negative psychological impact on them. Here is an example of the comments made by an Iranian participant:

#### **Iranian Participant:**

This quote refers to an Iranian woman who was on antiepileptic drugs, (sodium valproate). She talked about the undesirable outcome of not taking her medication which led her parents to be overprotective towards her. Her mother kept checking up on her every day, asking whether she had taken her medication, and this kind of behavior led her to feel like a child, and over-protected which was embarrassing for her.

She felt unhappy because she was not allowed to independently regulate her own obligations in life, such as taking her medication. It appears her mother's behavior towards her, made her lose her independence, as it seems that she started to be dependent on her mother in terms of taking her medication. She had not previously been used to being constantly chased by others. Below is her comment:

**Iranian Participant:**

P2.1.30

*I was at a party (...); I had a seizure (...). I forgot to take my drug (...). Since then my parents have been sensitive about my medication. They've been watching my steps just in case I forget my medicine. When I go out, my Mum says don't forget to take your medicine. I'm saying 'Mum, I'm not a child', she treats me like a kid. I'm not happy. I didn't used to be under the control of somebody else (page4, line59-72).*

**Sub-theme 5.3: Insufficient financial support**

The findings suggest that half of the Iranian participants felt they never receive financial help from the government or other organisations. This sub-theme therefore emerged only amongst Iranian participants. To some extent, epilepsy did affect Iranian participants financially. Five participants felt that they were living with no financial support, whether this was insufficiency of funds from their family or from the government. This resulted in participants experiencing serious economic problems. In countries like Iran, people have to pay for their medication which is very demanding for most people on a limited income; hence, they face challenges to be able to afford the medication. Here are some examples of the comments made by the Iranian participants:

**Iranian Participant:**

The following quote refers to an Iranian man whose epilepsy restricted him financially affecting him in a major way. Although he already had medical records, unfortunately

he was unable to receive public funds towards the cost of medication and this situation led him to experience financial hardship. It seems that living with epilepsy for him was demanding; and on top of this problem, he was not able to afford the cost of his medication. High expenditure depleted his resources and led him to be unable to pay for his medication on his own. Financial problems appear to be serious for this man. He laments:

P10.2.45:

*I don't get any financial help (...). Everyone is responsible for their medication costs, or scans. I'm not coming from a rich family! (...) My medication costs are high and not affordable for me. I've applied to some organisations to get funds, but I was told that I must give them proof of my illness, which I should get from court (...). Although I have medical records, still they don't accept it (page5, line100-110).*

### **Iranian Participant:**

The following quote is from an Iranian man who lost his life insurance policy due to his epilepsy. His family members would not receive a life insurance payment if anything happened to him because the policy had been stopped and he felt threatened by this. It appears that people with epilepsy in Iran do not receive sufficient insurance and this can be damaging to individuals with epilepsy. He also pointed out the lack of financial support towards the cost of medication from health organisations, meaning he had to meet the costs himself.

The participant lost his job due to having epilepsy, and on top of that he lost his life insurance which presented itself as a huge issue for the participant in terms of living with the illness.

P 5.2.50:

*My family and I don't have insurance. The company took me out of their contract (...), which is quite threatening. My wife and my children they are under my responsibility and now they are not insured. We also don't receive any financial support from health organisations (...) (page5, line97-105).*



## **Discussion**

The current study aimed at answering the research question, ‘In what way do people with epilepsy in Iran experience their life with epilepsy?’ This has been achieved through interviews with Iranian participants, which led to the development of several themes that examined the experience of living with epilepsy in an Iranian cultural setting. The investigations into the experience of living with epilepsy, to the best of the researcher’s knowledge, have not been previously reported; therefore, this study is the first attempt to explore how people experience living with epilepsy in Iran.

### **Social comparison influences on chronic illness**

Overall the findings appear to support the Social Comparison Theory (Festinger, 1954), referring to the need for comparison in unclear circumstances. In particular, individuals when in threatening circumstances prefer to make comparisons with others to evaluate themselves (Gibbon et al., 2000; Bennenbroek et al., 2002; Brakel et al., 2012). The outcomes of the current study showed that the Iranian participants appeared to compare themselves socially with others who were better-off and so perceived negative feelings, such as feeling down or disappointed, as a consequence. This finding is similar to the UK group in chapter 5. This means that participants felt dissimilar to their target groups, (White et al., 2006; Dibb & Yardley, 2006; Arigo et al., 2014). This study found that epilepsy as a neurological chronic illness may cause disruption in a person’s life. It is possible that people feel threatened in such circumstances; this may lead them to engage in negative social comparison (upward). The finding also supports the Identification/Contrast model (Buunk & Ybema, 1997); indicating that Iranians with epilepsy rather than identifying with better-off targets contrasted with fortunate others, which in turn, leads them to perceive negative effects. The negative impact of social comparison (upward), and its association with depression was evident in an earlier research by Buunk et al. (2006) amongst those with spinal cord injury; where depression was perceived as a consequence of upward contrast comparison. Bogart and Helgeson (2000), also found support for negative social comparison (upward), amongst women with breast cancer and reported that

whilst downward positive comparison was more likely to be associated with positive effects, upward contrast was linked to negative psychological outcomes. This was confirmed earlier by Wilson et al. (1997), who examined the impact of social comparison amongst individuals with sickle cell disease. It was suggested that patients tend to make comparison towards their peers and perceive negative psychological consequences, such as depression. Since the nature of the illness consists of recurrent pain, patients who compared to fortunate others, experienced high levels of depression and long term pain (Wilson et al., 1997). Therefore, it can be speculated that the more engaging in upward negative comparison, the less psychological well-being may be perceived amongst Iranian people.

Social comparison as a process has previously been evident in various chronic illnesses where it affected the perception of quality of life amongst those living with chronic illness. A study of Meniere's disease found support for social comparison influences on the perception of quality of life (Dibb & Yardley, 2006). It was shown that engaging in downward positive comparison was associated with positive adjustment and hence perceived a better quality of life. In addition, a study amongst cancer survivors reported those assimilating with an upward target and contrasting with a downward target were associated with a better perception of quality of life (Buunk et al., 1990; Bellizzi et al., 2006). Another study amongst people with spinal cord injury supports the positive effects of interpretation of social comparisons as coping mechanisms in the adjustment process amongst patients (Dibb et al., 2014), reporting that positive comparison has a positive impact on the individuals' perspective. More social comparison effects are evident even in neurological settings, such as, Multiple Sclerosis (Hemphill, 1989; Dilorenzo et al., 2008); highlighting the positive interpretation of social comparison and its association with better perception of quality of life. However this study is novel, as it is a first attempt to show the social comparison influences amongst people living with chronic illness in Iran, in particular epilepsy. Therefore the researcher will contribute to the growing body of knowledge for examining the Social Comparison Theory in the neurological setting; particularly epilepsy to understand the ways in which people can perceive their quality of life in Iran.

### **Psychological consequences**

In the context of epilepsy research, this study also found that psychological factors, such as fear and anxiety are associated with the experience of an epileptic seizure. Consistent with this, previous studies argued the unpredictable nature of a seizure may cause anxiety and fear as a consequence (Baker, 2002; Jacoby et al., 2005; Baker et al., 2005; Ekinici, 2011; Baker et al., 2013). In addition, Ekinici (2011) stated that fear of developing their next seizure may lead a person to experience social isolation. It is known that living with epilepsy may lead a person to feel uncertainty which has a foundation on the unpredictable nature of their seizures (Stanton et al., 2007; Baker et al., 2013). Consistent with this, the current study found that some of the Iranian participants felt uncertain as they were not aware of seizure recurrence. This uncertainty (Stanton et al., 2007; Baker, 2002; Hills, 2007), and lack of control of an epileptic seizure (Gaitatzis et al., 2004; Jacoby et al., 2005; Baker et al., 2005; Ekinici, 2011; Baker et al., 2013), led them to experience anxiety.

Although there is insufficient literature for epilepsy research in Iran, a recent study from Iran confirms a higher prevalence of anxiety amongst Iranian people with epilepsy than is found in the general population, and argued there is a profound interaction between epilepsy and anxiety (Maroufi et al., 2014). The prevalence of fear and anxiety in epilepsy has also been evident in previous research (Johnson et al., 2004; Goldstein & Harden, 2000; Kanner & Palac, 2002; Beyenburg et al., 2005).

### **Somatic consequence**

This study showed that some Iranian individuals with epilepsy may pass urine during their seizures. This is consistent with previous literature (Télliez-Zenteno et al., 2005; Brigo et al., 2013) signifying urinary incontinence as a chronic comorbid sign of epilepsy. This somatic symptom has received much more clinical attention (Peguero et al., 1995; Dworetzky et al., 2005; Timary et al., 2002), and much less is known about its psychological influences. This study revealed that perceived anxiety may have interaction with incontinence in some way. Consistent with this, previous studies

found the relationship between anxiety and urinary incontinence amongst the general population (Bogner et al., 2002; Stauber et al., 2007; Sinclair & Ramsay, 2011; Abrams et al., 2010), which in turn, leads to several psychosocial consequences, such as shame, embarrassment, social isolation, anxiety and depression (Molinuevo & Batista-Miranda, 2012). It must be acknowledged that people with epilepsy only pass urine during an epileptic seizure; however, elderly people or others with different chronic illnesses may experience incontinence throughout the whole day.

### *Social consequences*

The impact of epilepsy is much more than a seizure (Jacoby, 2000; Baker, 2002). Consistent with this, the current study found that Iranians perceived they were stigmatised by living with epilepsy. This could mean that epilepsy is still treated as an offensive and unpleasant illness in a Middle Eastern culture (Muthaffar & Jan, 2014). This may have a foundation on the traditional ‘taboo’ of epilepsy which led some individuals to have negative attitudes towards people with this chronic illness. Previous Iranian studies (Vanzan & Paladin, 1992; Valizadeh et al., 2013), showed that epilepsy has been considered as one of the most stigmatised illnesses in Iran. Evidence for this is provided by an Iranian study of Hosseini et al. (2011); suggesting that patients tended to conceal their illness due to the misconception and attached stigma of epilepsy. This was because the negative impression of epilepsy led patients to feel ashamed.

The stigmatising nature of epilepsy and the misconceptions about this neurological illness are not exclusive to Iranian society; Studies from the Middle East support the idea of the effect of stigma, particularly in the United Arab Emirates and Kuwait (Awad, & Sarkhoo, 2008; Muthaffar & Jan, 2014). This research highlighted the negative attitude of people towards epilepsy in Arab society and indicated that epilepsy still is still believed to be related to evil spirits, a mysterious source and psychological disturbance which causes people to conceal their illness in the majority of cases, and therefore perceive negative behaviour. The authors highlighted the significance of public awareness in their societies, in particular in schools. In line with this, WHO (2010), reported almost 85% of those living with epilepsy live in

developing countries, where they encountered the misconception of their neurological illness. Studies from European countries also support the stigmatising nature of epilepsy (Suurmeijer et al., 2001; De Boer et al., 2008; Taylor et al., 2011), and suggested that health professionals should take psychosocial functioning of patients into account, as they have a significant impact on the patient's quality of life.

Epilepsy as a chronic illness has various limitations (Bishop & Allen, 2003). Consistent with this, the current study found that Iranians appeared to have no independence as the nature of the illness restricted them in many ways. Lack of autonomy and feeling overprotected were common reported problems from participants. Previous literature supports the social barriers of living with epilepsy (Livneh, et al., 2001); signifying that individuals with epilepsy have restrictions in their regular life activities. Insufficient independence was reported in previous literature (Jacoby, 2000; Baker, 2002; Kerr et al., 2011). In addition in this study unemployment was shown to be another social barrier amongst those living with epilepsy in Iran. In line with previous literature unemployment rates were high amongst people living with epilepsy (Smeets et al., 2007; Jacoby & Austin, 2007), with double the unemployment rate amongst the general population. It is known that unemployment is associated with a poorer perception of quality of life (Jacoby et al., 2015) indicating that the more individuals being unemployed the worse their quality of life has been perceived.

Recent Iranian studies highlighted the significance of the unemployment rate amongst those living with epilepsy and stated that social discrimination such as divorce and unemployment, led to the majority of Iranian patients concealing their illness (Hosseini et al., 2010; Zamani et al., 2014). These problems, in turn, could lead patients to experience financial difficulties (Heo et al., 2009). Consistent with this, the current study found that a great number of Iranians experienced financial problems as a negative consequence of living with epilepsy. Although there is insufficient literature in Iran to explore financial difficulties of people with epilepsy, the previous Iranian study (Hosseini et al., 2010), confirmed the financial problems of patients and stated that patients were eager to seek financial help from governmental institutions to cover their medication costs. It can be argued that there are much more psychological

and social difficulties than the seizure itself, amongst Iranian patients which require taking into consideration. Therefore this study is going to add to the growing body of Iranian literature through discovering such difficulties.

#### 6.4 Conclusion

Overall, this study found that Iranian people with epilepsy were more engaged in negative upward comparison, which led them to feel dejected and perceive negative consequences, such as embarrassment and shame. This could mean that those living with epilepsy, in order to evaluate themselves, were eager to compare themselves to others who are better-off. In addition, it was shown that the unpredictable nature of an epileptic seizure may lead a person to feel scared and anxious. This could lead to a perception with psychological consequences. Living with epilepsy as a neurological condition does not just cover psychological consequences but it also consists of impaired psychosocial functioning, such as misconceptions about epilepsy, unemployment and lack of autonomy in Iranian society. Financial difficulties should not be neglected as a substantial problem of Iranian people with epilepsy. All the psychological and social consequences of living with epilepsy found in this study are in line with previous literature (Baker, 2002; Hosseini et al., 2010; Zamani et al., 2014; Jacoby et al., 2015) signifying that poor psychological well-being and social misconceptions and restrictions have a profound impact on the poorer perception of quality of life amongst those living with epilepsy.

This exploratory study found many different and important feelings from Iranian participants who expressed their negative experiences of living with epilepsy. The findings have implications for the Social Comparison Theory which to date has been examined in different types of chronic illnesses. Yet this study is unique in showing how the social comparison process can in fact impact on epilepsy as a chronic illness and in particular in Iran. It was also found that the passing of urine for some of the Iranian participants was an extra burden of living with this chronic illness, due to the shame and embarrassment associated with it. Considering all of the misunderstandings

about epilepsy, unemployment rates and financial difficulties of Iranian people with epilepsy; it can be understood that epilepsy for the Iranian population is much more than a seizure itself. Looking at the negative impact of epilepsy on an Iranian's life, makes it an excellent context to explore how and in what way people cope with the issues attached to their seizures. Therefore in order to have a comprehensive view of living with epilepsy, another exploratory study is necessary to investigate coping strategies applied to epilepsy in Iran. The next study will explore how and in what way Iranian people with epilepsy cope with their illness.

## **6.5 Study Two**

The previous exploratory study showed that Iranian individuals with epilepsy appeared to perceive considerable challenges in their life with this neurological chronic illness. These particular findings inspired the researcher to conduct further investigations to understand how people with epilepsy cope with their illness, in particular with unexpected seizures and their potential challenges. In addition, being diagnosed with a chronic illness means changing what you were to what you will be, alongside the day to day activities of leading your life. This indicates a process of adaptation not just on physical, also on psychological and social domains (Jacoby, 2000; Bishop, 2005), therefore it is important to understand the coping concepts and how people can evaluate their circumstance and deal with it using different coping strategies found in Iranian society.

### **6.5.1 Aim of the Study**

The main objective of this study was to explore how Iranian people with epilepsy cope with their illness. In particular, this study focused on what helps individuals to cope with seizures and urinary incontinence.

## 6.5.2 Method

### 6.5.2.1 Research Design

In the current study, a qualitative approach was used. For the purpose of this study the use of an in-depth interview as a method of data collection was decided upon.

### 6.5.2.2 Participants

The sample involved ten participants (5 female and 5 male), who were members of the 'Iranian Epilepsy Society' in Iran. All of these participants met the inclusion criteria for this study; they were required to be aged over 18 years, and have Iranian nationality, with a confirmed diagnosis of epilepsy. Iranian participants' ages ranged from 20 to 45 years ( $M=32.70$ ,  $SD=8.99$ ). The mean years of diagnosis of Iranian participants were 12.70 (min= 0, max= 20).

### 6.5.2.3 Sampling Strategy

The opportunistic sampling technique was applied. The semi-structured interviews with Iranian participants took place at the neurological hospital in Tabriz, in an out-patients' clinic. The participants took part in the research on a voluntary basis. The researcher was supervised all the time by specialists, to prevent any misunderstanding between interviewee and interviewer; however each volunteer after agreeing to participate in the study, was taken to a separate room for the purpose of privacy and being in a comfortable environment.

### 6.5.2.4 Procedure

Ethical approval for the second study was obtained from Brunel Psychology Research Ethics Committee (Appendix B). Prior to participating in the interview, participants were requested to sign a consent form (Appendix G), and they were also issued with participants information sheet (Appendix F). By the end of the interview session,



participants were offered the debriefing form to obtain more knowledge related to epilepsy (Appendix G). All participants were informed about the confidentiality of the procedure and that their name will be kept anonymous. They were also told that they are free to leave at any time.

#### *6.5.2.4.1 Interview Schedule*

A semi-structured interview was adopted for the Iranian participants with epilepsy. Iranians appeared to be conservative, due to cultural sensitivities and so all interviews lasted no more than 45 minutes. All of the interview data was digitally recorded. In order to develop a rapport between interviewee and interviewer the interview began with a brief explanation of the interview, where the participants were reassured that the researcher is not going to embarrass anyone with unnecessary questions (Willig, 2001). Also participants were informed that they were free whenever they wanted to leave the interview session. The interview schedule consisted of open-ended questions (Willig, 2001) (Appendix I). In general, five questions were asked. All the interview questions were taken from existing literature on coping strategies. The content of the questions were divided into four sections. The first section was demographic questions including; age, sex, ethnicity, type of epilepsy, and time since the participants diagnosis with epilepsy. The first parts of the questions were broad and generic in a way that the related questions were not sensitive. The second section of the questions were related to coping strategies participants used in living with their illness, for instance, they were asked, 'Can you tell me how do you cope with your epilepsy?' To see what type of coping strategies can be used amongst the Iranian participants. Also what was helpful for them in terms of adapting to these coping strategies? Question like 'What do you think is helpful when you are coping with your illness?' Was the related question to see what type of support and help participants received in Iranian society?

The third section of the interview was based on questions that dealt with the issues linked to urinary incontinence during their seizures. Participants were asked whether they were passing urine during the seizure or not. Questions like 'Are you passing urine during the seizure? If so how do you cope with it?' indicated that if any

participant was incontinent, then how they would cope with the problem. In order to see what helps or hinders the participants in terms of passing urine associated with their seizures, the last question was ‘What do you think is helpful when you are coping with incontinency? These evaluating questions (Spradley, 1979), were helpful as they enabled the researcher to compare responses.

## 6.6 Results and Discussion

### 6.6.1 Data Analysis

Thematic analysis was used to develop two main themes, where the emerged themes were able to answer the research question: ‘in what way do people with epilepsy cope with their illness; in particular, with their urinary incontinence?’ Each main theme description is provided and is interpreted through the selected direct quotes from all participants. Table 5, shows the main themes, each with sub-themes, emerged from interviews in Iran .1) Promoting positive adjustment 2) Religious coping.

**Table 5 Outlines of each theme and corresponding sub-themes for study 2 (Iran)**

Themes	Sub-themes
1. Promoting positive adjustment	1.1 Emotional expression 1.2 Social support
2. Religious coping	

#### **Theme 1: Promoting positive adjustment**

This main theme emerged amongst the Iranian participants. Some helpful factors have been mentioned that might impact on how participants cope with epilepsy in a good way. Many of the participants pointed to specific strategies when explaining how they

coped with their epilepsy. These strategies were considered as ways of coping with epilepsy as they appeared to help participants adjust themselves to their chronic condition. Thus promoting positive adjustment emerged as the first main theme which is comprised of two sub-themes: 'emotion expression', 'social support'. The selective quotes are as an example of responses that fit with the emergent sub-themes.

### **Sub-theme1.1 Emotion Expression**

Some of the participants felt living with epilepsy would be debilitating for them, and any out-bursting of emotions could be helpful in terms of coping and adjusting to one's chronic illness. With this in mind, out-bursting of emotions should be taken into account as it appeared to help participants with epilepsy to emotionally cope with their circumstances. Four female participants applied emotional expression strategies to calm themselves. This could be either crying or becoming angry which appears to help participants feel relaxed and satisfied after their emotion is released. Here are some examples of comments that were made by Iranian participants:

#### **Iranian Participant:**

The following quote refers to an Iranian woman who found crying to be a helpful coping strategy because she felt better after crying. She further discussed her view of feeling stressed because she was not able to cry in front of her friends, yet as soon as she was alone she released her emotion through crying. It can be said that being alone may help her to release her emotion as she felt inhibited by the presence of others, where it appeared that she needed to be alone. It seems that her emotional response to the stressor had perceived positive consequences. Also it appears that being emotional during the adaptation process helped her to cope well with her illness.

P8.1.20

*I do cry a lot which helps me to feel much better. (...)I'd never cry in front of others. So that's why I'd prefer to stay by myself alone at home. Once I developed seizure when I was with my friends (...), but I couldn't cry and*

*wanted to leave party (...). When I got home, I cried loudly (...) then I felt much better. My seizures always end up with crying; at least I can release my emotion and feel relaxed (page3, line32-55).*

### **Iranian Participant:**

The following quote refers to another Iranian woman who expressed her emotion with anger. She felt that it did not matter if being angry affected her marital relationship or led her to be named as an aggressive person; at least she could use this strategy as a coping technique and release her emotions. It seems that she could release her emotion through displays of anger, and she felt that she could cope well since she perceived satisfaction with the out-burst of her emotion. It appears that she lets her emotion come out freely, which may in turn help her to adjust herself to her illness.

P4.1.45

*My mood could change easily, I get angry so often and it affects my marital life (...). I've had a conflict with my husband on every single topic (...). Normally it happens after a seizure. (...) Sometimes getting angry works for me as I can easily express my emotion; although some of my friends have labeled me as an aggressive person, I don't care, as long as I have some ways to relieve my emotion, I'm happy (page3, line30-45).*

### **Sub-theme1.2 Social Support**

Some of the participants felt that coming to terms with epilepsy could be challenging. Yet if individuals have supportive resources, this could provide relief for them. Four participants (2 male & 2 female), agreed that they received greater social support after their epilepsy was diagnosed. It was understood these supportive resources do have an important influence on the participants' quality of life. Some of them mentioned their parents as the main supportive body and others referred to their partners. Some of the participants explained how calm and understanding their family were. Here are the typical examples of the Iranian participants:

**Iranian Participant:**

In this quote an Iranian woman explained the sufficient social support which she received from her mother. She commented especially how calm and understanding her mother was. It appears that being understood by her family was an amazing feeling for her, and she felt relieved to have her mother's support. She felt that she could cope well and perceive positive consequences, as she appeared to feel fortunate.

P3.1.35

*I have received the best support ever from my Mum (...); she has been always helpful she looks after me very well. She understands me (...) and I'm lucky to have her in my life. With her, I've never felt alone (...), I do cope well as I've received amazing support from her; she buys me everything I need (page3.line47-58).*

**Iranian participant:**

The following quote refers to an Iranian man who felt that the type of support from his wife reduced any perceived threat of embarrassment and shame especially at home. It appears he was satisfied with the support from his wife, which was helpful for him in that he felt he could manage his illness in a good way. His wife's support led him to feel supported which resulted in positive consequences for him as he was less likely to isolate himself due to embarrassment or shame. It appears that he received help from his wife on a practical and emotional level. This suggests that building up a good relationship with partners might be considered a way of coping since the person can feel safe and secure without the thought of being mocked.

P5.2.40

*Fortunately I've got an amazing wife (...). When I get seizure; she never let kids to know what's going around (...). I've developed good relationship with her, she is one in million, she's always saying like you're not alone we are in this together and this sort of things makes me feel like yeah I'm able to manage my illness (page 3,line48-71).*

## **Theme 2: Religious Coping**

This main theme emerged amongst the Iranian participants, when they were asked how they cope with their incontinence. Three participants (2 male & 1 female), reported their incontinence and felt that engaging in religious activity helped them to cope with their urinary incontinence. It appears that religious support could be helpful to tackle such demanding circumstances, particularly in living with long-lasting illnesses including unexpected events, such as developing a seizure and passing urine in the process.

They performed different religious activities, for example, going to mosque, staying at holy shrines for praying, and keeping written prayers with them. This theme was found only amongst the Iranian participants and may be because they were all Muslims and they had strong beliefs in God. Here are some examples of the comments made by the Iranian participants:

### **Iranian Participant:**

The following quote refers to an Iranian woman who passed urine during her seizure. She felt that her religious beliefs helped her to cope with her condition. She further believed that her beliefs had a main role to play where it empowered her to deal with her illness, especially with passing urine. Although urinary pass appears not to be an easy issue for others, this woman felt calm and peaceful when she prayed to God. Perhaps she believed God would rescue her as she held strong beliefs.

P1.1.20:

*My belief can rescue me (...). I believe that God can help me to deal with incontinence and is the only one who can protect me. I do pray a lot because I strongly believe that if I pray regularly and have a strong bond with God, then I feel more relaxed, and strong enough (page4, line68-79).*

### **Iranian Participant:**

The next quote refers to an Iranian man, who expressed his positive emotion in terms of perceiving God as a powerful coping resource. He appeared to feel relaxed and calm in terms of his religious activities either by going to holy shrines or by taking written prayers. He discerns that religiosity had an influence on him such that it helped him not only to adjust himself positively to his incontinence, but also brought hope to him since he hoped for a cure. It appeared that his strong belief in God made him believe that his urinary problem is curable.

P2.2.43:

*I do believe that God can cure my incontinence and I pray every day because praying keeps me alive (...). I always keep written prayers (...) I believe that those written words will help me to not pass urine in public. I'm going to mosque and praying there. I have gone so many times to Imam Hossein's shrines (...) and felt better. Praying has great impact on my life (page4, line70-84).*

### **Discussion**

The aim of the current study was to explore coping strategies amongst people with epilepsy in Iran. Specifically, the current study aimed to answer the research questions 'in what ways do people in Iran cope with epilepsy?' 'How do they cope with their incontinence?' This has been achieved through the development of the themes from interviews with the Iranian participants. The comments by each participant were influenced by their own experiences. To the best of the researcher's knowledge, these expressions had not been previously reported to describe the experience of living with epilepsy within this cultural setting.

*Promoting positive adjustment* was the first main theme emerging amongst the Iranian participants. It covered 'emotional expression' and 'social support'. Iranians used these techniques in order to decrease their stress in confronting their chronic condition and adjusting themselves in the best possible way. Overall, the findings support the emotion-

focused coping theory (Folkman & Lazarus, 1980); performing to regulate emotions associated with stressful events, such as emotional expressions, (Folkman & Lazarus 1980). Consistent with this, the current study showed that Iranian participants were eager to deal with their circumstance more emotionally. It appeared they were more likely to use more of the emotion-focused coping strategies in dealing with epilepsy. This could mean that the more releasing of emotion, the more feeling relieved perceived amongst Iranians. The findings were confirmed earlier by Folkman and Lazarus (1980); who suggested that if the stressor is perceived as an uncontrollable event, then the emotion-focused forms of coping increase which, in turn, appear to be successful in terms of venting emotions and lowering distress (Roth & Cohen, 1986). This could indicate that Iranian people perceived the illness as a more stressful and threatening object. Emotional expression as a coping strategy has received attention in health difficulties and chronic illnesses (Folkman & Lazarus, 1985; Oosterhuis, 1999; Piazzini et al., 2007). Consistent with this, Iranian people perceived that; instead of making practical changes, they could be satisfied through releasing their emotions either with crying or anger. The findings are supported by previous Iranian research which highlighted the emotional expression as the most common types of coping strategies amongst Iranian people with epilepsy (Hosseini et al., 2010). However, Livneh et al. (2001) confirmed emotion-focused coping strategies as maladaptive coping mechanisms, which may be associated with the negative effect on the adjustment process to threatening event, in particular with epilepsy. The authors stated that crying or venting emotion is associated with emotional expression which in turn helps the person to adapt themselves to threatening circumstances. However, if it persists for longer; this type of coping may turn to be maladaptive coping strategy. This could mean that emotional expression which occurs as a coping strategy, may contribute to less psychological well-being (Goldstein et al., 2005; Westerhuis et al., 2011). This is because Iranians appear to perceive their illness as an uncontrollable stressful event. Goldstein and colleagues (2005) reported that the more using of emotion-focused coping strategies, the high the level of anxiety was perceived amongst individuals with epilepsy. Myres et al. (2013) also found support for depressive symptoms amongst patients with non-epileptic seizures, as they were engaged in emotion-focused coping strategies. Therefore, it can be speculated that the more emotion-focused coping strategies are used amongst Iranians, the more the psychological difficulties are going to be perceived.



In addition, this study found that Iranians appeared to perceive sufficient social support from their family members. This could mean that the more an individual feels supported by family members, the more they perceive that they feel adjusted to their epilepsy (Westerhuis et al., 2011). This was confirmed by a recent study (Bautista et al., 2013), which showed patients with epilepsy tended to seek support from others, and found this helpful as a coping strategy. This was because they felt satisfied and well-adjusted to epilepsy with perceived social support. This highlights the role of family function in managing the illness, where Iranian people felt happy in terms of receiving emotional support from them, as this support could empower them to manage their illness in the best possible way. This is in line with previous findings of Hosseini et al. (2010), conducted in Iran and emphasised the role of the family function, and argued that family care is one of the main determinants of psychological well-being and therefore, improving quality of life amongst people with epilepsy. Earlier, Folkman and Lazarus (1988) considered seeking social support as a positive coping mechanism. This could mean that feeling protected and supported by family members, may lead individuals to feel better adjusted to their illness, which in turn could help them to perceive a better quality of life as a result (Goldstein et al., 2005; Westerhuis et al., 2011). In addition seeking support from others was evident in a study of Bautista et al. (2013) who examined coping strategies amongst people with epilepsy. They highlighted social support as one of the active management coping strategies to the medical condition amongst epilepsy patients.

A recent study highlighted the significance of the religious coping strategy as an active coping mechanism for people with epilepsy (Tedrus et al., 2013). Consistent with this, the current study found that Iranians were eager to cope with their epilepsy, in particular with their incontinence through their strong beliefs in God.

The *Religious coping* strategy was the second main theme which emerged in this study. Participants felt that having strong beliefs in God could rescue them from negative thoughts and help them think about positive consequences. This could mean that they felt better adjusted when they empowered themselves with their strong beliefs (Bautista et al., 2013). As a matter of fact, Iranian people sought to use more religious coping

strategies, to actively manage their condition, in a way receiving help from God appeared to be a belief to accepting their illness.

Perhaps, since almost all of the Iranian population is Muslim, it could be an implication as religiosity was part of the nature of being Muslim. This is in line with previous Iranian study (Hosseini et al., 2010); highlighting religious beliefs as an active coping mechanism. This is because it empowered patients to accept their illness. It was also recognised that there is always a possibility amongst individuals to classify religious coping as a positive way of dealing with difficult circumstances, as this strategy provides valuable outcomes, for instance solve the person's issue with the great help of God (Thune'-Boylea et al., 2006). There is evidence that religious beliefs could help people with breast cancer in the USA and European countries (Thune'-Boylea et al., 2006); also amongst Chilean women with breast cancer (Choumanova et al., 2006). They further reported that more than 80% of the recent studies have highlighted the influence of religious coping, as a mechanism, on the better psychological consequence in people living with chronic illnesses. Carver et al. (1989), supported the importance of religious coping as a strategy in living with chronic illness, and stated that patients mostly are eager to do religious activities as an emotional support. This is because turning to religion assists them to manage their specific stressors. It can be said that despite the growing body of knowledge to understand the psychological adjustment and well-being of a person with epilepsy, finding a solution to urinary passage during the seizure, remain a main issue to epilepsy population. This may have essential implications for individuals coping in relation to incontinency, where people learn to adjust themselves to their issue by empowering themselves through their strong religious beliefs. It is important to note that there are different approaches to spirituality and it does not necessarily mean that there is a relationship with God. Despite the different approaches however Coyle (2002), points out that meaning and purpose is common amongst them. It engenders positive states of mind, a sense of control, motivate action, empower and provide hope which appears to help in the coping process through difficult times. Though spirituality is highly subjective (Coyle, 2002), we cannot downplay its significance in peoples' lives especially in Iran, where individuals tend to be highly religious and spiritual, thus when diagnosed with an illness, especially epilepsy which is tends to be chronic, there is a tendency to

seek meaning or healing from the power source of the religious beliefs or their spirituality.

## 6.7 Conclusion

It can be concluded that participants in Iran appeared to perceive the illness as an uncontrollable stressor. This is because they appeared to use the emotion-focused coping strategies, such as emotional expression which, in turn, covers a person's emotional response rather than making practical changes. It is possible that epilepsy for Iranians had a negative effect as they appraised the illness as a threatening event. This would explain why problem-focused coping strategies were not reported amongst Iranian samples. It can be concluded that this negative perception of an illness may be linked to lower perceived quality of life amongst the Iranian sample. This careful investigation is important in improving coping efforts, filling in the gaps and detangling some of the complexities involved in coping.

Since the principle aim of this thesis is to examine the role of social comparison on the perception of quality of life amongst people living with epilepsy in Iran and the United Kingdom, qualitative studies are not adequate to predict influencing factors in peoples' life, in living with a chronic illness. To determine better predictors of quality of life, the influence of social comparison needs to be assessed statistically amongst a larger epilepsy population. For this purpose, the influencing factors comprise: physical aspect (severity of seizure), psychological aspects (self-esteem & anxiety), and social aspects (social comparison processes). Social comparison dimensions and their effects have been previously examined with other chronic illnesses, such as Meniere's disease (Dibb & Yardley, 2006), cancer (Buunk, et al., 1990; Bogart & Helgeson, 2000; Bellizzi et al., 2006) and Multiple Sclerosis (Dilorenzo et al., 2008). Psychological factors, such as self-esteem and anxiety as suggested by previous researchers (Alwash et al., 2000; Suurmeijer et al., 2001; Baker, 2002; Johnson et al., 2004; Zeber et al., 2007; Barahmand & Haji, 2014), can predict quality of life in epilepsy. The impact of seizure severity has been well-documented (Bautista & Glen, 2009), indicating severity of seizure leads to a decreased quality of life. However, this research is on its first attempt to see whether the

interpretation of social comparison dimensions, after controlling for seizure severity and psychological factors can predict quality of life amongst people with epilepsy who live in Iran and the United Kingdom. These influencing factors, as well as demographic characteristics will be included in the next study. The next chapter will show how social comparison can influence the ways in which quality of life has been perceived amongst individuals living with epilepsy in Iran and the United Kingdom.

## CHAPTER 7: QUANTITATIVE ANALYSIS OF SURVEY (STUDY3)

### 7.1 Introduction

The review of literature for quality of life in Chapter 2 discussed the multidimensional nature of quality of life and how different aspects of quality of life should be measured in order to have a holistic understanding of the construct. In line with this, one measure was used in this study to capture subjective aspects for quality of life construct in people with epilepsy. This aspect includes the impact of an illness on multiple dimensions of health status, such as physical, psychological and social domains (Cramer, 2002).

It is known that the physical domains have an influence on quality of life in epilepsy (Harden et al., 2007); the more experience of seizures, the less quality of life was perceived. Therefore, a measure of seizure severity was considered to be essential.

The psychological domains are highlighted as important to quality of life for a person living with epilepsy (Baker, 2002); indicating the lowered quality of life which was associated with perceived anxiety and poor self-esteem. So examination of these domains was considered in this study.

Social domains have also been highlighted in literature on epilepsy as important areas (Elliot & Richardson, 2014); however to date, studies have focused on social environments and the social functioning of people with epilepsy. Therefore this is a new approach to examine social comparison in this domain. In addition following on from the results in chapter five (Study 1), where the qualitative data showed that people with epilepsy were socially comparing, the quantitative approach was chosen to statistically test the true effect of interpretation for social comparison dimensions on the perception of an individual's quality of life.

This chapter begins with the aims, research questions, method, and the results of the third phase of the thesis investigations and are presented here. It will be followed with discussion.

## 7.2 Aims

The aim of this cross-sectional analysis was to determine whether social comparison dimensions significantly predict quality of life amongst people with epilepsy in the United Kingdom and Iran. This can be done after controlling the demographic characteristics, seizure severity and psychological variables (self-esteem, anxiety), that the literature previously, highlighted as key impact factors on quality of life amongst people living with epilepsy.

## 7.4 Research Question

Does social comparison influence the quality of life for people with epilepsy living in Iran and the United Kingdom?

### 7.4.1 Sub-question

Is there a difference between perception of quality of life of people living with epilepsy in Iran and the United Kingdom?

## 7.5 Method

### 7.5.1 Research Design

A cross-sectional design was used in this study. The rationale for this cross-sectional design was that it enables the researcher to carry out the study within a specific time, and it is also relatively inexpensive (Levin, 2006). Although using the cross-sectional design is a snapshot of the illness, it allows an understanding of the association between variables. However no causal relationship can be answered as any indication for sequence of events cannot be found (Levin, 2006). If the purpose of this study was an intervention to see some effects before, during or after the specific onset of the illness, then a longitudinal design would have been used as the more appropriate research design.

### *7.5.2 Participants*

The sample involved 203 participants who were members of ‘The Epilepsy Research UK,’ in the United Kingdom and the ‘Iranian Epilepsy Society,’ in Iran. All participants engaged on a voluntary basis. There were 103 Iranian participants (46 male and 57 female), and 100 British participants (40 male and 60 female). All of the participants met the inclusion criteria for this study; they were required to be aged over 18 years, and have Iranian nationality for the Iranian study and have British nationality for the study in the United Kingdom. They needed to have a confirmed diagnosis of epilepsy.

In the United Kingdom the average age is in the lower 40s, range from 18 to 78 ( $M=43.28$ ,  $SD=13.12$ ). The Iranian group’s average age is in the high 30s, range from 18 to 66 ( $M=39.74$ ,  $SD=12.11$ ). Therefore the mean age of the two countries was similar. Urinary incontinence was seen slightly more in Iran than in the United Kingdom ( $N=23$  UK,  $N=28$  Iran). Time since diagnosis with epilepsy in Iran ( $M=14.84$ ,  $SD=12.81$ ) and was however lower than that in the United Kingdom ( $M=20.23$ ,  $SD=14.84$ ). The table for demographics variables is shown in (Appendix N).

### *7.5.3 Procedure*

Ethical approval for the present study was obtained from Brunel Psychology Research Ethics Committee (Appendix B). With regard to the Iranian policy, the permission to do research for the entire thesis was granted from the head of the East Azerbaijan Epilepsy Association which is located in a neurological hospital in Tabriz, Iran (Appendix C).

The researcher used different data collection strategies in each country. In Iran, participants were recruited in an outpatient clinic at the neurological hospital in Tabriz. With the help of the clinician, people who met the inclusion criteria were informed by the clinician that a study was taking place. The clinician introduced the researcher to the participants, and those who agreed to participate were asked to sign a consent form (Appendix K). The participants were then given paper questionnaires, and the process

took around 25-30 minutes. All the paper copies of the questionnaires were collected by the researcher. Finding the participants in Iran took one week; the researcher attended the out-patient clinic every day during the week with the help of the clinician to find volunteers to participate in the research.

For the United Kingdom's sample, the researcher used an online Survey (Survey Monkey) in order to recruit participants. It is worth noting that the 'Epilepsy Research UK' charity was helpful in terms of finding the participants in the United Kingdom (Appendix J). The charity advertised the researcher's survey in their online monthly magazines. The completion of the online survey for each participant took approximately 20-25 minutes. Participants were asked to sign a consent form prior to completing the questionnaires (Appendix K).

#### *7.5.4 Research materials*

##### *7.5.4.1 Measures*

The questionnaires consisted of five scales, namely; The Hospital Anxiety and Depression Scale (Zigmond & Snaith, 1983), the Quality of Life in Epilepsy Inventory- 31 (Cramer et al., 1998), the Self-Esteem Scale (The Rosenberg's, 1965), the Social Comparison Scale (Van der Zee et al., 2000), and the Seizure Severity Questionnaire (Cramer et al., 2002) (Appendix L). In order to administer these questionnaires for the Iranian sample, a standard forward-backward translation method was used to translate all of the questionnaires to the Persian language (Appendix M). A bilingual English-Persian translator reviewed all of the questionnaires for the purpose of accuracy (Bradley, 1994). A different person translated them into Persian. And another independent translator translated them back from Persian to English to ensure nothing was lost in translation (Cella, Lloyd, & Wright, 1996).



## Independent Variables

### *Social Comparison*

The identification/Contrast scale (Van der Zee et al., 2000), is a scale which measures social comparison with 12 items. This questionnaire measures the degree to which a person agrees or disagrees with all 12 items. Respondents were required to read the items and specify how much they agreed with the comparison statements on a 5- point Likert scale: Strongly agree, Agree, Disagree, Strongly disagree, Not at all. These 12 items were structured into four subscales: 'downward identification' (3 items), 'downward contrast' (3 items), 'upward identification' (3 items), and 'upward contrast' (3 items). This scale measures identification - the degree to which you feel similar to another person and contrast - the degree to which you feel different (Van der Zee et al., 2000). Positive interpretation of social comparison dimensions consists of upward identification items. For example, items include: *'when I meet others who are experiencing less problems than I am, it makes me happy realizing that it is possible for me to improve'*. For downward contrast, items include: *'when I see others who experience more difficulties than I do, I feel relieved about my own situation'*.

However negative interpretation of social comparison dimensions involves upward contrast, for example, *'when I think about others who are doing better than I am, I feel frustrated about my own situation'* and downward identification, for instance, *'when I see others who are doing worse, I experience fear that my health status will decline'* (Van der Zee et al., 2000). This scale is commonly used in assessing social comparison dimensions in relation to coping strategies (Dibb & Yardley, 2006).

The reported internal consistency ranged between 0.88 and 0.93. The reliability and validity of this scale is well documented (Van der Zee et al., 2000). This scale is a well-used scale, and has been validated in Meniere's disease as a chronic illness (Dibb & Yardley, 2006).

### *Anxiety*

The Anxiety subscale of the Hospital Anxiety and Depression Scale (Zigmond & Snaith, 1983) was used to measure anxiety in the current study. Respondents were required to read the 7 items for anxiety and specify how much they agreed with the statements on a 4-point Likert scale: Strongly agree, Agree, Disagree, Strongly disagree. The score range is 0-21 for each subscale. High scores represent high levels of perceived anxiety and low scores shows low levels of perceived anxiety. The anxiety subscales were found to be internally consistent with values of Cronbach's coefficient at 0.80 in a normal population based study in Norway (Mykletun, Stordal, & Dahl, 2001). In particular, Bjellanda, Dahlb, Haug, and Neckelmann (2002), systematically reviewed the literature and reported Cronbach's alpha for anxiety (HADS-A)  $\alpha= 0.83$ . It is well documented that this scale has also been used broadly in clinical practice in people living with epilepsy (Baker et al., 1993; Kimiskidis & Valeta, 2012).

### *Self-Esteem*

The self-esteem was measured by the Self-Esteem Scale (Rosenberg's, 1965) (RSES) which measures an individual's self-esteem using ten items. Respondents were asked to read each of the items and to indicate how much they agreed or disagreed with the statements on a 4-point Likert scale. Items were based on 4 ranges: Strongly agree, Agree, Disagree, Strongly disagree. Scores involve 4 ranges: Scores between 15 and 25 are within normal ranges; scores below 15 suggest low self-esteem; and more than 25 suggest high self-esteem. The internal consistency was reported to be 0.88 (Blascovich & Tomaka, 1991), and studies investigating people with uncomplicated epilepsy, have reported a reliability of 0.82 (Gauffin et al., 2010). RSES was translated to the Persian language and its reliability was a reported 0.84 (Shapurian, Hojat, & Nayerahmadi, 1987). This scale has been applied in different cross-cultural studies (Schmitt & Allik, 2005), and has been used in other epilepsy studies (Baker et al., 1993; May & Pfafflin, 2002; Baker et al., 2005; Gauffin et al., 2010).

### *Seizure Severity*

The Seizure Severity Questionnaire (Cramer et al., 2002), classifies epileptic seizures into four phases: phase 1 involves items related to an event prior to having a seizure: Warning ‘aura’ (2 items); phase 2 consists of items related to activity during a seizure: ictal activity (3 items movement; 2 items for altered consciousness, without movement); and phase 3 contains items associated with after a seizure: postictal recovery (1 item). The recovery phase is further subdivided into three elements: Cognitive (4 items), Emotion (4 items), Physical (4 items). Finally, phase 4 involves items related to overall the assessment ‘severity and bother’ (3 items). All items were scored on a 7-point Likert scale to indicate frequency: never (1) to always (7); severity: very mild (1) to very severe (7); bothersome: no bother (1) to very bothersome (7). High scores indicate a worse status and low scores represent better condition. In the current study a total score of seizure severity was calculated which has an acceptable reliability coefficient 0.76, and test–retest reliability coefficient 0.74 (Cramer et al., 2002). This scale is usually used in measuring the severity of seizures in people with epilepsy (Cramer et al., 2002). This scale has also been widely used in other epilepsy related studies to indicate the impact of depression on quality of life for people with epilepsy (Cramer, Blum, Reed, & Fanning, 2003).

### *Items measuring demographical information*

Participants in both countries also completed general demographical questions, which comprised of: age (continuous), gender (Male= 1, Female =2), time since diagnosis (years of living with epilepsy) (continuous), and at the end they were asked to confirm whether they were passing urine during their seizures or not (Yes= 1, No= 2).

### *Dependent Variable*

#### *Quality of Life*

Quality of life was measured by the Quality of Life in Epilepsy Inventory-31 QOLIE-31 (Cramer et al., 1998) which is a well-used brief scale derived from the original longer illness inventory; the quality of Life in Epilepsy Inventory-89 (QOLIE-89,

Devinsky et al., 1995). In this study, the QOLIE-31 scale was used as this short-version was easy to fill in and time saving and it was also more convenient for participants. The researcher hoped it would help prevent attrition in the number of participants. This scale involves 31 items structured into seven subscales: Seizure worry (5 items), Overall Quality of Life (2 items), Emotional Well-Being (5 items), Energy/Fatigue (4 items), Cognitive Functioning (6 items), Medication Effects (3 items), and Social Functioning (5 items), and also an overall score. Higher scores reflected better quality of life, and lower scores showed poor quality of life; ranging from 1 to 100. In order to calculate these differences, all the scores were converted from raw numeric values to scores of 0-100 points, where high converted scores represented a better quality of life. An overall score was calculated by weighting score times its weight and summing over all scales (Cramer et al., 1998). Question 31 is a personal assessment of the individuals' general health status which is not included in the total quality of life score (Todorova, Velikova, Kaprelyan, & Tsekov, 2013). Internal consistency scores were reported to range between 0.77 and 0.85 with test-retest reliability ranging from 0.64-0.85 (Cramer et al., 1998). The reliability and validity of this scale is well documented by Cramer and colleagues (1998). Cronbach's alpha for the Persian version of this questionnaire (QOLIE-31-P) was a reported 0.90 (Mohammadi, Kian, Davoudi, Nia, & Nojomi 2013). In the current study a total score of quality of life was calculated (Cramer et al., 1998). This scale has been used in a wide range of the clinical research in order to assess quality of life in people with epilepsy (Cramer et al., 1998; Hardan et al., 2007; Yue et al., 2011; Todorova et al., 2013).

## 7.6 Questionnaire Design

Chapter 2 explained the requirement for measuring quality of life which is a main construct of this thesis. This was necessary in order to find an appropriate measure to cover the 'multidimensional' aspects of quality of life, as it relates to epilepsy. The definition of quality of life, referred to physical, psychological and social aspects (Cramer et al., 1998; Cramer, 2002); therefore, a questionnaire which could measure quality of life and is underpinned by the multiple dimensions of epilepsy studies was

required. Several questionnaires were considered. For example: 1) epilepsy-specific instruments which is referred to the Epilepsy Surgery Inventory-55 (ESI-55) (Selai, Elstner, & Trimble, 1999) and the Washington Psychosocial Seizure Inventory (WPSI) (Dodrill, Batzel, Queisser, & Temkin 1980). However, neither of them were appropriate for the current study. The ESI-55 is a scale which is only designed for epilepsy surgery patients. The WPSI is an interview-based questionnaire, which does not cover important areas for quality of life, such as cognitive and physical functioning, energy, and overall quality of life. 2) Generic instruments were also considered which included the Short Form Health Survey (SF-36) (Ware, Snow, Kosinski, & Gandek, 1993) and SF-12 (Ware, Keller, & Kosinski, 1998). However, neither of them were HRQOL scales to measure health domains of perceived quality of life in epilepsy.

It should be noted that SF-36 was the generic core for the epilepsy-specific scales, particularly for the quality of life scale of the current study (Birbeck, Kim, Hays, & Vickrey, 2000). In this study, the quality of Life in Epilepsy-31 (QOLIE-31) (Cramer et al., 1998) was used. It was derived from the original Quality of Life in Epilepsy-89 (QOLIE -89) (Devinsky et al., 1995). In total, two subscales (Energy/fatigue & Emotional well-being) of the QOLIE-31 questionnaire were derived from SF-36, which covered nine questions.

Birbeck et al. (2000) compared the SF-36 and SF-12 scales with the QOLIE -31 and QOLIE -89 scales, and stated that the QOLIE is an epilepsy-specific scale which covers the SF-36 as a generic core. They suggested that epilepsy-specific scales and health-related quality of life scales were preferable to generic scales, as the epilepsy-specific questionnaires had larger responsiveness index than the SF-36 and SF-12 (Birbeck et al., 2000). Therefore, SF-36 and SF-12 were not used in this thesis.

In addition, the short version of QOLIE -10 which later was developed by Cramer, Arrigo, Van Hammée, and Bromfield (2000), was considered. Although it takes five minutes to complete this questionnaire, Cramer et al. (2000) highlighted the QOLIE -31 was the preferable scale, because it included more detailed information. The rationale for using the QOLIE -31 was that it can be adapted into different cultural

settings. It can also evaluate health related quality of life (HRQOL) domains of concern amongst individuals with epilepsy (Cramer et al., 1998).

## 7.7 Data Analysis

Analyses were conducted using the Statistical Package, Version 20. In order to do statistical analysis, the data was checked initially in terms of their distribution. Based on the Skewness Kurtosis test, data were found to be normally distributed where the values of the skew and kurtosis were zero (Field, 2013) (Appendix O).

Correlations of variables are presented to show the relationship between the variables. A hierarchical multiple regression, was conducted on the data for quality of life, with social comparison, anxiety, self-esteem and seizure severity as the independent variables. The rationale for a hierarchical multiple regression was that it allows the researcher to enter the variables based on the theoretical frameworks (Field, 2013). Furthermore, this method allows each independent variable to be evaluated on what it can add to the model after each entered variable is controlled for (Pallant, 2013). Therefore, the theoretical basis is that the interpretation of social comparison dimensions would add a large amount of unique variance to quality of life once psychological factors (self-esteem and anxiety), and physical factors (seizure severity) have been controlled for.

In order to conduct a hierarchical multiple regression, the relevant assumptions of this statistical analysis must be examined initially. A sample size of over 100 was deemed acceptable, given there were seven independent variables to be involved in the analysis (Tabachnick & Fidell, 2001). The assumption of multi-collinearity has been met, since collinearity statistics, namely Tolerance and VIF were all accepted (Coakes, 2005). Mahalanobis distance scores showed no multivariate outliers. Scatter plots and Residual confirmed the assumptions of normality, linearity and homoscedasticity (Pallant, 2013).

## 7.8 Results and Discussion

Demographic Characteristics of the participant is shown in Appendix (N). The means and standard deviation of the variables are shown in Table 4 below for samples from the United Kingdom and Iran. Cronbach alpha coefficient was calculated for each scale in this study and also presented in the table below.

**Table 4 Descriptive Statistics of study variables in participants of the UK and Iran**

	UK				Iran			
	N	Mean (SD)	Min/Max	$\alpha$	N	Mean(SD)	Min/Max	$\alpha$
Quality of life	100	50.30 (18.47)	2.97/93.30	0.92	103	39.96( 20.01)	3.83/79.98	0.94
Anxiety	100	9.980(5.07)	.00/19.00	0.87	103	12.56(4.16)	1.00/19.00	0.79
Self-esteem	100	16.08(7.31)	.00/30.00	0.92	103	12.50(6.88)	.00/28.00	0.89
Seizure severity	≠61	4.53(1.29)	1.53/6.79	0.87	≠77	4.53(0.94)	2.03/6.20	0.76
Social comparison sub-scales:								
Downward identification	≠97	7.75(4.28)	3.00/15.00	0.76	103	9.42(2.86)	3.00/15.00	0.67
Downward contrast	≠97	10.10(3.28)	3.00/15.00		103	10.92(2.60)	4.00/15.00	
Upward identification	≠97	9.83(3.41)	3.00/15.00		103	10.26(3.13)	3.00/15.00	
Upward contrast	≠97	8.77(4.01)	3.00/15.00		103	10.70(3.06)	3.00/15.00	

≠Note: numbers less than 100 due to missing data

Based on the descriptive statistics, higher scores for quality of life were reported amongst the participants from the United Kingdom than from the Iranians. Anxiety was higher in Iran than in the United Kingdom.

Higher self-esteem was reported more amongst the participants from the United Kingdom than from the participants from Iran. However, equal scores were reported in seizure severity in the both countries.

Participants in the United Kingdom and Iran reported making more downward contrast comparisons (feeling positive after comparison with someone worse-off). However feeling negative after downward identification comparison was reported slightly more in Iran than the United Kingdom.

In Iran slightly more people reported feeling positive after upward identification comparison than in the United Kingdom. This pattern was similar for upward contrast comparison, where Iranian people were more likely to report negative feelings after upward contrast comparison (comparing with someone better-off).

### **Research Model**

Previous research showed that demographic characteristics, except urinary incontinence (age, sex, time since diagnosis), clinical status and psychological status influenced the quality of life for people living with epilepsy. Therefore, in order to identify the true effects of social comparison dimensions, the social comparison variables were brought in the last step of hierarchical regression.

After entering the demographic variables (Block 1), variables determining the physical status and representing biological aspects involved in seizure severity was entered into the analysis (Block 2). Next, variables representing the psychological aspects consisting of self-esteem and anxiety, were entered into the analysis (Block 3). This was followed by social variables comprised of four social comparison dimensions (Block 4). This assumption has been reflected in the hierarchical biopsychosocial model, shown in Table 5, and can be found as an extension of Elliot and Richardson (2014) ‘biopsychosocial model of epilepsy’ (see Chapter 2). The variables entered hierarchically into the analysis are based on the theoretical model.



**Table 5 Research Model**

Main concepts	
Block 1	Demographic status (Age, sex, time since diagnose, urinary insentience )
Block 2	Physical (clinical) status (Seizure severity)
Block 3	Psychological status (Self-esteem and anxiety)
Block 4	Social domains (Upward identification, upward contrast, downward identification, downward contrast)

**7.8.1 The United Kingdom Study**

Intercorrelations between the multiple regression variables in order to predict quality of life in the samples from the United Kingdom are reported in Table 6 and the regression statistics are in Table 7.

**Table 6 Pearson coefficient correlation between variable of study in the UK**

	1	2	3	4	5	6	7	8	9	10	11
1.Quality of life	1										
2.Age	.32**	1									
3.Gender	.13	.05	1								
4.Time since diagnosis	.35**	.48**	.04	1							
5.Urinary incontinence	.09	.04	-.05	-.04	1						
6. Seizure severity	-.54**	-.07	-.03	-.11	-.23	1					
7.Self-esteem	.68**	.31**	.16	.23*	.35**	-.46**	1				
8.Anxiety	-.59**	-.37**	-.18	-.20*	-.33**	.39**	-.73**	1			
9.Downward identification	-.48**	-.08	-.16	-.13	-.32**	.58**	-.58**	.59**	1		
10.Downward contrast	.11	.03	.05	-.02	-.23*	-.18	.24*	-.01	-.17	1	
11.Upward identification	.24*	.07	.01	.14	-.28**	-.13	.12	.04	-.04	.42**	1
12.Upward contrast	-.50**	-.21*	-.10	-.18	-.35**	.43**	-.57**	.53**	.54**	-.01	-.18

\*  $P < 0.05$ , \*\*  $P < 0.01$

Pearson Coefficient Correlations in the United Kingdom's sample show there is a significant negative correlation between seizure severity and quality of life. This indicates that people with increased seizure severity perceived a poorer quality of life. There was a significant positive correlation between self-esteem and quality of life which shows that people with higher self-esteem had a better quality of life. A large significant inverse relationship was shown between anxiety and quality of life which suggests highly anxious people perceived a poorer quality of life. Downward identification was negatively associated with quality of life. This means the more an individual felt negative after comparison with a worse-off target, the worse the quality of life was perceived.

There was a significant positive relationship between upward identification comparison and quality of life which indicates that feeling positive after comparison with someone better-off was related to perceiving a better quality of life. However, a significant inverse correlation was shown between upward comparison contrast and quality of life which means that comparing with someone better-off led people to perceive negative feelings and have a poorer quality of life. There was no significant relationship found between downward comparison contrast and quality of life. This suggests that feeling positive after comparing with someone worse-off was not associated with quality of life.

Urinary incontinence was positively correlated with self-esteem and negatively associated with anxiety. This could mean those who pass urine during a seizure had high self-esteem, and were less anxious. Other variable correlations were shown in the matrix table.

In order to test the hypotheses for the United Kingdom's sample, a four step hierarchical multiple regression was conducted with quality of life as the dependent variable.

Age, gender, time since diagnosis and urinary incontinence were entered at step one of the regression to control demographic characteristics. Seizure severity was entered

at step two. Psychological variables (self-esteem and anxiety) were entered at step three and finally social comparison dimensions (upward contrast comparison, upward identification comparison, downward contrast comparison, downward identification comparison), were entered at step four.

The hierarchical multiple regression in the United Kingdom (Table 7), showed that at step one, all demographic characteristics, did significantly contribute to the regression model and accounted for 17% of the variation in quality of life. However, the beta values for demographic variables show there were no significant predictors for quality of life.

Introducing seizure severity in the second step, explained an additional 23% of variation in quality of life and this change in  $R^2$  was significant  $F(1, 53) = 21.44$ ,  $p < 0.001$ . The beta value was negatively associated with quality of life which means high seizure severity is associated with poorer quality of life.

Adding psychological variables to the regression model in the third step, explained an additional 20% of variation in quality of life and this change in  $R^2$  was significant  $F(2.51) = 13.21$ ,  $p < 0.001$ . The beta value for seizure severity was significant which was negatively associated with quality of life. This means that although psychological variables explained an additional variation in quality of life, seizure severity still can account for quality of life significantly. This means that those with high seizure severity perceived a poorer quality of life. The beta value for self-esteem was significant, which was positively associated with quality of life. It means that those high in self-esteem perceived a better quality of life than those with low scores on this variable.

Finally, the addition of the social comparison dimensions to the regression model explained an extra 2% of the variance for that step in quality of life of the United Kingdom's samples. The change in  $R^2$ , however, was not significant  $F(4, 47) = 0.94$ ,  $p > 0.05$ . This means that social comparison dimensions was not influencing the quality of life of the United Kingdom's samples. When all variables were included at stage four of the regression model, seizure severity and self-esteem were significant

predictors of quality of life. The beta value for seizure severity was significant, and was negatively related to quality of life. The beta value for self-esteem was significant, and was negatively predicting quality of life. The whole model accounted for a total of 62% of the variance (Appendix P)

Although, social comparison dimensions were not accounting for quality of life amongst the United Kingdom's samples, an interpretation of comparison dimensions is still interesting. The last step showed that the interpretation of downward contrast (feeling positive after comparing with someone worse-off), and upward identification (feeling positive after comparing with someone better-off), did not lead the United Kingdom's participants to perceive a better quality of life. This could mean that positive social comparison was not influencing the United Kingdom's samples' quality of life; however, the interpretation of downward identification (feeling negative after comparing with someone worse-off), and upward contrast (feeling negative after comparing with someone better-off), did not affect the quality of life amongst the United Kingdom's samples. In general, this could mean that the interpretation of social comparison dimensions did not affect the perceived quality of life amongst the United Kingdom's participants.

**Table 7 Summary of four-step Hierarchical Regression Analysis for Variables predicting quality of life in the UK**

Predictor	$\Delta R^2$	$\beta$
Step 1	.17	
* Age		.18
Gender		.11
Time since diagnosis		.26
Urinary incontinence		.10
Step 2	.23**	
Age		.17
Gender		.09
Time since diagnosis		.20
Urinary incontinence		-.01
Seizure severity		-.50**
Step 3	.20**	
Age		.01
Gender		-.03
Time since diagnosis		.16
Urinary incontinence		-.18
Seizure severity		-.28**
Self-esteem		.44**
Anxiety		-.17
Step 4	.02	
Age		.016
Gender		.00
Time since diagnosis		.13
Urinary incontinency		-.19
Seizure severity		-.28*
Self-esteem		.48**
Anxiety		-.14
Downward identification		.008
Downward contrast		-.16
Upward identification		.13
Upward contrast		-.05
Total $R^2$	.62**	
$n$	100	

\* \*\* $P < 0.001$ , \* $< 0.05$

#### *7.8.1.1 Testing Hypotheses for the United Kingdom's study*

The social comparison dimensions did not significantly account for quality of life, which means that social comparison did not affect the perception of quality of life of the United Kingdom's samples. Therefore, Hypothesis 1 is not supported for the United Kingdom sample. Anxiety did not significantly account for the quality of life of the United Kingdom sample; therefore, Hypothesis 2 is not supported. However, seizure severity was a negative significant predictor of quality of life of the United Kingdom sample which means that seizure severity has a negative effect on the perception of quality of life of the United Kingdom's people with epilepsy. This finding therefore supports Hypothesis 3. In addition, self-esteem was a significant positive predictor of quality of life amongst the United Kingdom sample; indicating that those with high self-esteem perceive a better perception of quality of life in the United Kingdom's sample. Thus, Hypothesis 4 is supported.

#### *7.8.1.2 Mediator and Moderator in the United Kingdom*

Previous research has shown that psychological variable, such as self-esteem and anxiety can mediate the effect of the social comparison process (reviewed in Chapter 3). Therefore, since social comparison did not predict quality of life in the United Kingdom sample; there may be some mediation that impacts the social comparison process. To do this, since self-esteem was significant in the hierarchical regressions, then examining the effect of self-esteem was considered in the United Kingdom study. However, anxiety did not predict quality of life. Therefore, mediation and moderation were not tested for anxiety.

To do this, mediating factors were tested according to Baron and Kenny's (1986), method. In order to determine whether self-esteem was mediating the effects of social comparison dimensions in the United Kingdom, three separate regressions were conducted with outcome measures. In the first regression, self-esteem was entered into the equation; in the second regression, the social comparison dimensions were entered into the equation. Then in the third regression, both independent variables were entered into the equation. Mediation is shown by variables, whilst the two first

regressions indicated significant regressions, the last regression equation was not significant. It is shown that self-esteem has mediated upward contrast and downward identification comparisons' effects on the perception of quality of life for individuals with epilepsy in the United Kingdom.

Moderating influences were also tested. In order to calculate the moderating variable in the United Kingdom, the independent variables were centred based on Baron and Kenny's (1986), method. This consisted of subtracting each variable from each mean. The self-esteem was multiplied by the four social comparison variables. The interaction effects were added to the regression model (Block 2), along with the previous model. There was a moderating relationship, when the interaction of self-esteem and social comparison dimensions affects quality of life. The model with the interaction between social comparison dimensions and self-esteem accounted for significantly more variance than just social comparison dimensions and self-esteem as separate variables,  $R^2$  change= .14,  $p= .000$ , indicating that there is a significant moderation between social comparison dimensions and level of self-esteem on perceiving quality of life amongst the United Kingdom's participants. This means that self-esteem interacted with downward contrast to have a negative effect on perceiving quality of life (beta= -.19,  $p< .01$ ). Self-esteem interacted with upward identification to have a negative effect on perceiving quality of life (beta= -.22,  $p< 0.005$ ). Self-esteem also interacted with upward contrast to have a negative effect on perceiving quality of life (beta= -.29,  $p<.000$ ). There was a significant moderation between social comparison dimensions and levels of self-esteem on overall quality of life amongst people living with epilepsy in the UK (Appendix T).

The negative effects of upward contrast and downward identification on quality of life were mediated by self-esteem in the United Kingdom's study. This indicates that high self-esteem can help reduce the negative feelings experienced after interpreting negative comparison, either with worse-off or better-off targets. Tests for interaction showed a buffering effect of feeling positive after comparison to worse off individuals can predict quality of life, however, it depends on the level of self-esteem that person has. High levels of self-esteem would decrease the effect of downward positive comparison's interpretations on the perceived quality of life amongst people with

epilepsy in the United Kingdom. Also, high self-esteem would decrease the effect of feeling positive after comparison to fortunate others. It can argue that self-esteem is the moderator in the relationship between social comparisons' dimensions and the perceived quality of life in the United Kingdom's study.

### 7.8.2 Iranian Study

Intercorrelations between the multiple regression variables in order to predict quality of life in the Iranian samples are reported in Table 8 and the regression statistics are in Table 9.

**Table 8 Pearson coefficient correlation between variable of study in Iran**

\*  $P < 0.05$ , \*\*  $P < 0.01$

	1	2	3	4	5	6	7	8	9	10	11
1. Quality of life	1										
2. Age	.17	1									
3. Gender	.14	-.05	1								
4. Time since diagnosis	-.18	.14	-.05	1							
5. Urinary incontinence	-.27**	.06	.02	.20*	1						
6. Seizure severity	-.36**	-.03	-.02	.05	.06	1					
7. Self-esteem	.69**	.02	.21*	-.08	-.28**	-.50**	1				
8. Anxiety	-.47**	-.15	-.14	.05	.15	.41**	-.55**	1			
9. Downward identification	-.08	.05	.03	.05	.03	.48**	-.30**	.21*	1		
10. Downward contrast	-.03	.09	.01	-.04	.07	-.10	.07	.04	-.08	1	
11. Upward identification	.30**	.24*	.01	-.12	-.15	-.05	.07	.01	.21*	.33**	1
12. Upward contrast	-.48**	-.10	-.03	-.01	.19*	.30**	-.53**	.40**	.17	.14	-.12

Pearson Coefficient Correlations in the Iranian samples show there is a significant negative correlation between urinary incontinence and quality of life which means the more one is incontinent, the poorer the perception of quality of life. A large significant inverse relationship was found between urinary incontinence and self-esteem. This could mean that those who passed urine during a seizure were more likely to have lowered self-esteem. A significant inverse correlation was shown between seizure severity and quality of life which indicates that high seizure severity is linked to a worse quality of life. A significant positive correlation was seen between self-esteem and quality of life. This means that high self-esteem is associated with a better quality of life. Anxiety showed a significant inverse relationship with quality of life which



means that the higher the level of perceived anxiety, a poorer quality of life was perceived. There was a significant positive correlation between upward identification and quality of life. This indicates that feeling positive after comparing with someone better-off was associated with a better perception of quality of life. A significant inverse relationship was seen between upward comparison contrast and quality of life this means that negatively interpretation of someone better-off, the worse the quality of life that was perceived. There were no significant correlations between downward comparison dimensions and quality of life. This could mean that comparison to someone worse-off and interpreting this comparison either positively or negatively was not associated with quality of life in Iran. Other variable correlations are shown in matrix table.

In order to test the hypotheses for the Iranian sample (Table 9), a four step hierarchical multiple regression was conducted with quality of life as the dependent variable. This test is done in a similar way to the UK sample. Age, gender, time since diagnosis and urinary incontinence were entered at step one of the regression to control for the demographic characteristics. Seizure severity was entered at step two. Psychological variables (self-esteem and anxiety), were entered at step three and finally the social comparison dimensions (upward contrast comparison, upward identification comparison, downward contrast comparison, downward identification comparison), were entered at step four.

The hierarchical multiple regression for the Iranian data show that at step one all demographic characteristics did significantly contribute to the regression model and accounted for 15% of the variance in quality of life. The beta value for urinary incontinence was a significant predictor of quality of life which was negatively associated with quality of life, meaning that the more incontinent an individual, the poorer the quality of life was perceived. Introducing the seizure severity at the second step, explained an additional 10% of variation in quality of life and this change in  $R^2$  was significant  $F(1, 71) = 10.32, p < 0.001$ . The beta value for seizure severity was significant which was negatively related to quality of life, which means that experiencing more seizures is associated with a perceived poorer quality of life.

Adding psychological variables to the regression model in the third step, explained an additional 27% of variation in quality of life and this change in  $R^2$  was significant  $F(2,69) = 20.49, p < 0.001$ . The beta value for self-esteem was significant, which was positively associated with quality of life. Participants with high self-esteem perceived a better quality of life. Finally, the addition of social comparison dimensions to the regression model explained 7% of the variation in quality of life and this change in  $R^2$  was significant  $F(4, 65) = 3.19, p < 0.05$ . When all variables were included at stage four of the regression model, self-esteem and upward identification comparison were significant predictors of quality of life. The beta value for self-esteem was significant which was positively related to quality of life. The beta value for upward identification comparison was positively associated with quality of life. The more individuals compared themselves to fortunate others and interpreted this positively the better quality of life that was perceived. All four steps of the regression were significant, accounting for a total of 59% of the variance (Appendix Q).

Although, only upward comparison identification was accounting for quality of life amongst the Iranian samples, still interpretation of the other comparison dimensions would be interesting. The interpretation of downward and upward comparison contrast could have been a negative predictor of a better quality of life amongst people with epilepsy in Iran. However, interpretation of downward identification, could have positively predicted quality of life amongst Iranian samples.

**Table 9 Summary of four-steps Hierarchical Regression Analysis for Variables predicting quality of life in Iran**

Predictor	$\Delta R^2$	B
Step 1	.15*	
Age		.21
Gender		.14
Time since diagnosis		-.15
Urinary incontinence		-.25*
Step 2	.10 **	
Age		.20
Gender		.13
Time since diagnosis		-.13
Urinary incontinence		-.24*
Seizure severity		-.32**
Step 3	.27 **	
Age		.17*
Gender		.001
Time since diagnosis		-.13
Urinary incontinence		-.07
Seizure severity		.00
Self-esteem		.60**
Anxiety		-.09
Step 4	.07*	
Age		.11
Gender		-.002
Time since diagnosis		-.12
Urinary incontinence		-.01
Seizure severity		-.03
Self-esteem		.58**
Anxiety		-.08
Downward identification		.07
Downward contrast		-.15
Upward identification		.23*
Upward contrast		-.07
Total $R^2$	.59**	
$n$	103	

\*\* $P < 0.001$ , \* $< 0.05$

### *7.8.2.1 Testing Hypotheses for Iranian study*

The positive social comparison (upward), was a significant predictor of quality of life amongst the Iranian sample. This suggests that comparing to someone better-off, and interpreting this positively is associated with better perception of quality of life. So, Hypothesis 1 is supported, but for upward identification only. Anxiety did not significantly account for the perception of quality of life of the Iranian sample; therefore, Hypothesis 2 is not supported. Seizure severity did not significantly account for the perception of quality of life of the Iranian sample; hence, Hypothesis 3 is not supported. However, self-esteem was a significant positive predictor of the perception of quality of life amongst the Iranian sample, indicating that those with high self-esteem perceive a better quality of life, hence, supporting Hypothesis 4.

### *7.8.2.2 Mediator and Moderator in Iran*

Mediating factors were tested according to Baron and Kenny's (1986) method. Since in Iran, from four social comparison dimensions only upward identification was accounted for quality of life, therefore, the mediation test was performed to see whether self-esteem was mediating the effects of other three social comparison dimensions in Iran. Anxiety was not tested neither for mediation nor moderation effect; as it was not significant. To do this, three separate regressions were conducted with outcome measure. In the first regression, the self-esteem was entered to the equation; in the second regression, the three social comparison dimensions were entered to the equation. Then in the third regression, both independent variables were entered to the equation. Mediation is shown by variables, the two first regressions indicated significant regressions; however, the last regression equation was not significant. It is shown that self-esteem has mediated upward contrast comparison's effects on the perception of quality of life of individuals with epilepsy in Iran.

Moderating effects were also tested. In order to calculate the moderating variable in Iran, the independent variables were centred based on Baron and Kenny's (1986) method. This consisted of subtracting each variable from each mean. The self-esteem

was multiplied by the three social comparison variables. The interaction effects were added to the regression model (Block 2), along with the previous model. There was a moderating relationship, when self-esteem and three social comparison dimensions are multiplied effects of quality of life. The model with the interaction between social comparison dimensions and self-esteem accounted for significantly more variance than just three social comparison dimensions and self-esteem as separate variables,  $R^2$  change = .08,  $p = 0.000$ , indicating that there is a significant moderation between three social comparison dimensions and level of self-esteem on perceiving quality of life amongst Iranian participants. This means that self-esteem interacted with downward identification to have a negative effect on perceiving quality of life (beta = -.22,  $p < 0.002$ ). Self-esteem also interacted with downward contrast to have a negative effect on perceiving quality of life (beta = -.25,  $p < .001$ ). There was a significant moderation between two social comparison dimensions and level of self-esteem on overall quality of life amongst people living with epilepsy in Iran (Appendix S).

In Iran, the negative effect of upward contrast on perceived quality of life was mediated by self-esteem. This could mean that high levels of self-esteem can subside the negative feeling after comparison to a fortunate target. This mediation is partially similar to the study from the United Kingdom, where in both study groups high levels of self-esteem amongst people with epilepsy, can be effective in terms of perceiving negative feelings after comparison to fortunate others, such as people without epilepsy. In Iran, moderation was also significant. It was shown a buffering effect such as self-esteem increased the effect of downward comparison both positive and negative interpretations on perceived quality of life decreased amongst Iranians. I can conclude that self-esteem is the moderator in the relationship between social comparisons' dimensions and the perceived quality of life in Iranian study.

### 7.8.3 Differences between Groups

In order to identify the differences in quality of life between Iran's and the United Kingdom's participants, the multivariate analysis of variance (MANOVA), test was

conducted. The rationale behind this analysis was that it helps the researcher to compare the means between two groups of study (Field, 2013).

Table 10 shows the mean scores on anxiety, self-esteem, social comparison dimensions, quality of life and seizure severity for the two groups of study. MANOVA analysis shows a number of significant group differences. Group differences were apparent in anxiety ( $F(1,138) = 10.25, p < 0.01$ ), self-esteem ( $F(1,138) = 11.98, p < 0.01$ ), downward comparison identification ( $F(1,138) = 4.01, p < 0.05$ ), downward comparison contrast ( $F(1,138) = 6.68, p < 0.05$ ), upward comparison contrast ( $F(1,138) = 15.73, p < 0.001$ ), and total quality of life ( $F(1,138) = 15.12, p < 0.001$ ) (Appendix R).

The mean scores of anxiety were higher amongst the Iranian sample. This means that individuals in Iran perceive more anxiety than the people in the United Kingdom. The mean scores of downward comparison identification, downward comparison contrast, and upward comparison contrast amongst the Iranian participants were higher than the United Kingdom's participants. This indicates that people in Iran are more engaged in comparison to those better-off and perceive negative feelings. In addition, individuals were subjected to comparison with worse-off targets, and perceive either good or bad feelings. In general, it can be said that Iranian people were more likely to engage in comparison with others than people in the United Kingdom. However, the mean scores for self-esteem and quality of life were higher amongst the United Kingdom's participants in comparison to the Iranians. This could mean that the United Kingdom's participants have high self-esteem and perceive a better quality of life in comparison to the Iranian people with epilepsy. Interestingly, the groups did not differ in mean scores of upward comparison identification and seizure severity.

With regard to the research sub-question, the data suggests that there are differences in the perception of quality of life for people with epilepsy in the United Kingdom and Iran. The mean score of quality of life amongst the United Kingdom's sample was significantly higher than the Iranian sample.

**Table 10 The multivariate analysis of variance (MANOVA) in Iran and the UK**

Dependent Variables	UK a Mean (SD)	Iran b Mean (SD)	F(1,138)	Sig.	Partial Squared	Eta
Anxiety	10.80(4.44)	13.09(3.93)	10.25	.002	.07	
Self-esteem	15.55(7.05)	11.51(6.59)	11.98	.001	.08	
Downward identification	8.36(4.11)	9.54(2.81)	4.01	.04	.02	
Downward contrast	10.04(3.12)	11.24(2.31)	6.68	.01	.04	
Upward identification	9.754(3.52)	10.29(2.98)	.964	.32	.007	
Upward contrast	8.96(3.97)	11.23(2.71)	15.73	<.001	.10	
Quality of life	49.51(16.93)	37.01(20.10)	15.12	<.001	.10	
Seizure severity	4.53(1.29)	4.53(.94)	.001	.97	.001	

Note: a N= 77, b N= 61

## Discussion

The main aim of the current study was to examine factors that influence quality of life in people living with epilepsy in the United Kingdom and Iran. To the best of the researcher's knowledge, this study is the first attempt to investigate whether social comparison influenced the perception of quality of life of individuals living with epilepsy in the United Kingdom and Iran, after controlling seizure severity and psychological factors which have previously shown effects on the perception of quality of life. To do this, a separate test was performed for each country.

This study provides further evidence that the interpretation of positive social comparison (upward) influenced the perception of quality of life amongst Iranian people living with epilepsy. This means that comparison with better-off and feeling inspired and hopeful was associated with a better understanding of quality of life amongst Iranians. The finding supports the Identification/Contrast model (Buunk & Ybema, 1997); indicating that Iranian participants have identified with the better-off others which led them to perceive positive effects.

However, in the United Kingdom the perception of quality of life was shown to be negatively associated with seizure severity; signifying that the more experiences of

seizures, the worse quality of life was perceived amongst the British participants. Although self-esteem was mediating the effect of interpretation of social comparison dimensions on perceived quality of life amongst Iranian and British samples, it was found to be the most consistent predictor for perception of quality of life in both groups of study. This means that high self-esteem was associated with better perception of quality of life amongst Iranian and British people. This highlights the importance of psychological influences, namely self-esteem on the perception quality of life in two different countries.

### ***Social comparison influences on epilepsy in Iranian sample***

Overall, in the context of the social comparison influences on epilepsy as a chronic illness, the findings of this study add support to the Social Comparison Theory (Festinger, 1954) by examining this theory in epilepsy as a chronic illness. This study is novel, since no study previously tested this theory on epilepsy. The strongest influence of social comparison was upward social comparison that positively was associated with a better perception of quality of life amongst Iranians. This indicates that feeling positive after comparing to someone better-off, may improve perception of quality of life for Iranians. The significance of this variable adds support to the research which has shown that cancer patients perceived a better quality of life after seeing how well the other patients are doing, and interpreted this positively (Buunk et al., 1990). In addition, Van der Zee et al. (1998) found support for positive upward comparison amongst women with breast cancer; they preferred to achieve information from those better-off. Affiliate with fortunate others, and having contact with them has also been evident in the study of Taylor and Lobel (1989), amongst cancer patients. It was revealed that exposure to the better-off comparison targets affects the patients in a way their emotional functions, such as inspiration and optimism were increased. The finding is also consistent with previous research, showing that positive upward comparison provides motivation, for chronically ill patients, with useful information for self-enhancement (Blanton et al., 1999; Buunk et al., 2007). Engaging in positive upward comparison provides the person with required information that can be helpful in terms of self-improvement (Wood et al., 1985). The findings of the current study



suggest that quality of life represents the subjective evaluation of how individuals are doing and functioning in their life (Brakel et al., 2012). In this evaluation, Iranian people with epilepsy may compare themselves to others who are better-off to see how they are doing in comparison to them, and may perceive a better understanding of their life. It is possible that positive interpretation after comparing themselves to someone who is better-off has a substantial influence within Iranian society, as it could help people to feel inspired and motivated to be similar to that target which in turn can have a positive effect on perceiving a better quality of life (Taylor & Lobel, 1989). The result supports the Identification/Contrast model (Buunk & Ybema, 1997), indicating that Iranian participants have identified with fortunate others which led them to perceive positive effects on their perception of quality of life. Since positive social comparison (upward), did significantly account for perception of quality of life in Iran, the implication here might be that in Iran providing ‘positive role models’ for people with epilepsy has a substantial impact on perceiving a better quality of life (Taylor & Dakof, 1988). If people with epilepsy in Iran seek affiliation and follow positive role models as a comparison target it may help them to perceive an improved quality of life (Bennenbroek et al., 2002; Arigo et al., 2014). This may aid them to identify themselves with a fortunate target, for instance, well-adjusted patients and perceive positive consequences which results in an enhanced quality of life (Stanton et al., 1999), and self-improvement (Wood et al., 1985).

### ***Social comparison influences on epilepsy in the UK sample***

The social comparison dimensions, however, did not predict the quality of life in the United Kingdom’s study. This is because perhaps physical (clinical), and psychological domains appeared to be more important than the social domains in the United Kingdom’s study (this implies self-esteem which moderated the effect of the social comparison process in the United Kingdom). This is supported by the HRQOL model, indicating that physical and psychological domains were considered as the key factors in predicting quality of life in epilepsy (Cramer et al., 1998; Baker et al., 1993). However, the findings are inconsistent with previous studies; highlighting the importance of the social comparison interpretations, as the main predicting factor for

the perception of quality of life amongst those with Meniere's disease (Dibb & Yardley, 2006) and people with spinal cord injury (Dibb et al., 2013).

A negative interpretation of social comparison (downward) was associated with a lowered perception of quality of life amongst British people. This indicates that a negative feeling after comparison to worse-off targets resulted in a poorer perceived quality of life. The findings support the Identification/Contrast model of Buunk and Ybema (1997); indicating that British people identified themselves to worse-off targets and may feel fearful, and perceived a poorer quality of life as a consequence. This was confirmed later by Dibb and Yardley (2006); they highlighted a perception of lower quality of life amongst those who made negative comparisons with unfortunate others.

According to Buunk and Ybema (1997), individuals contrasted themselves to better-off targets and felt negative and perceived poorer quality of life as a consequence. This is consistent with the current study's findings where lowered perception of quality of life was perceived amongst those Iranians and British people who made comparison to fortunate others and felt dissimilar. Negative effects of social comparison (upward), was also evident by Bogart and Helgeson (2000), amongst women with breast cancer. They further argue that feeling negative in comparison to better-off targets for cancer patients was frustrating as they felt they would never be like those fortunate others.

Previous research (Brakel et al., 2012); showed an association between contrasting with downward targets and perceiving better quality of life amongst cancer survivors. However, this is inconsistent with the current study's findings. Neither Iranian nor British people compared themselves to worse-off targets positively; to have an understanding of their life in living with epilepsy. Positive interpretation of downward comparison and its impact on the perceived quality of life was also evident in a study of Dibb and Yardley (2006), amongst people with Meniere's disease, and Dibb et al. (2013), amongst patients with spinal cord injury; feeling better was achieved after comparison to a worse-off target.

### *Physical factor*

However, in the context of epilepsy research, the more an individual experienced a seizure led British people to have poorer perception for quality of life in living with epilepsy. This was found in the current study when quality of life, as an outcome measure, was negatively predicted by seizure severity in the United Kingdom's study.

Finding supports previous studies where the more severity of seizures highlighted the poorer the quality of life amongst people living with epilepsy (Jacoby, 2000; Harden et al., 2007; Adebayo et al., 2014). Previous research highlighted the importance of seizure severity, and the control of depression; it still contributed significantly (Harden et al., 2007). The authors stated that separation of severity of seizure and quality of life is almost impossible. The authors highlighted negative association between severity of seizure and poorer perception for quality of life amongst people with epilepsy, and further argued that experiencing more seizures led individuals to perceive anxiety, and lower perception of quality of life.

The significance of seizure severity in predicting quality of life provides a further contribution to the biopsychosocial model where the epilepsy-specific variables, such as seizure severity could have been a significant predictor if it was measured in the model (Elliott & Richardson, 2014).

Since seizure severity did negatively predict the perception for quality of life in the United Kingdom, it can be implied that when illness is managed, individuals with epilepsy may have their own independence, and hence, perceive a better quality of life (Harden et al., 2007). This is because anxiety may appear as a consequence of the frequent and severe seizures (Adebayo et al., 2014). In addition, seizure severity has been linked to social functioning of a person with epilepsy (Harden et al., 2007); therefore, illness management could help British people with epilepsy to avoid negative feelings of being isolated and career limitations.

### *Psychological factors*

Self-esteem was found to predict quality of life, positively both for Iranian and British samples. This could mean that high levels of self-esteem may result in a better perception for quality of life for both groups of study. The importance of psychological functioning, such as self-esteem, on perception for quality of life in living with epilepsy was well-documented (Suurmeijer et al., 2001; Baker, 2002; Zamani et al., 2014). Evidence for this is provided by Collings (1990) emphasised on self-esteem effect on perception of quality of life, and stated that lowered levels of self-esteem led patients with epilepsy to perceive poorer quality of life. This finding supports the previous research where psychological well-being, namely self-esteem had a positive impact on perceived quality of life for people with epilepsy (Jacoby, 2002; Baker, 2002).

It can be argued that as a consequence of their illness, individuals with epilepsy have encountered many challenges in their life and in a way they have understood that they are not able to do some tasks on their own (i.e. driving), and they are obliged to have some unavoidable facts in their illness, (i.e. taking medication). Perhaps, understanding that they have limited abilities in comparison to other people, this limitation might lead them to have low self-esteem which may in turn affect their quality of life (Baker et al., 2005).

Self-esteem, as a psychological variable, was the most consistent variable in the both groups. It has been found to mediate the social comparison process in both groups of study; in a way the negative effects of upward contrast and downward identification on perception of quality of life were mediated by self-esteem in the United Kingdom's study. This indicates that high self-esteem can help to reduce the negative feelings experienced after interpreting negative comparison, either with worse-off or better-off targets. This is supported by Buunk et al. (1990); they argued that people with high levels of self-esteem avoid interpreting the negative feelings of social comparison on both directions (either upward or downward). In addition, amongst the Iranians, the negative effect of upward contrast on perception of quality of life was mediated by self-esteem. This indicates that high self-esteem can reduce the negative feelings

being experienced after interpreting comparison with someone better-off. This is in line with an earlier study of Gibbons et al. (1991), highlighted that individuals with high self-esteem tend to do comparisons with better-off targets and interpret them positively. The findings are supported by the biopsychosocial model of epilepsy in which psychological and social domains accounted for quality of life more than physical domains (Elliott & Richardson, 2014).

Amongst the British people those who had high self-esteem acknowledged that they were passing urine. This was found in the current study, where urinary incontinence was positively associated with self-esteem. However those with lowered levels of self-esteem might deny or avoid disclosing that they were passing urine whilst having a seizure. In other words, they might refuse to believe that they were incontinent.

Likewise, anxiety variables explain why those who were anxious and hide their inconstancy just in case they are mocked by others. It is known that denial as a coping strategy has been linked to a better adaptation in the early stages of a stressful event, such as chronic illness (Livneh et al., 2001); as it minimises the level of perceived stress (Carver et al., 1989). Nonetheless, it would cause problems if it persisted for longer. This is because it will interrupt the adaptation process (Carver et al., 1989). However, in Iran, urinary incontinence was negatively associated with self-esteem. This difference between these countries could speculate that in Iran reporting urinary incontinence may affect an individual's self-esteem, whereas in the United Kingdom people were less forward in disclosing their incontinency; perhaps they gave priority to their self-esteem.

This study found that anxiety was negatively associated with the perception of quality of life for those with epilepsy in Iran and the United Kingdom. This indicates that in both countries the more perceived the anxiety; the poorer the quality of life was perceived. This is in line with previous research which highlighted the importance of anxiety in quality of life amongst people with epilepsy (Jacoby, 2000; Harden et al., 2007; Kimiskidis & Valetalead, 2012); signifying that the more anxiety perceived the less quality of life was reported. These results suggest there is a complex interaction

between anxiety and quality of life in epilepsy (Maroufi et al., 2014). This indicates the unpredictable nature of epilepsy leads a person to experience anxiety (Baker, 2002; Vazquez & Devinsky's, 2003; Jacoby et al., 2005; Ekinci, 2011). Anxiety also is associated with epilepsy specific factors, such as seizure frequency (Adewuya & Ola, 2005; Adebayo et al., 2014). This could mean that the more experiencing of seizures the higher level of anxiety may be perceived, which in turn affects the perception for quality of life (Beyenburg et al., 2005). In addition, psychological factors, such as fear of death in epilepsy may result in anxiety (Jacoby et al., 2005; Baker et al., 2005; Ekinci, 2011). It can be said that people with epilepsy may perceive anxiety and this influences their perception of quality of life. In general, the aetiology of anxiety in epilepsy is unknown, however, researchers assume that either the unpredictable nature of the seizures or the perceived loss of control, were possible causes (Jackson & Turkington, 2005).

### **Supported theories**

The findings of this study support the HRQOL theory in epilepsy (Baker et al., 1993), in which quality of life is a multidimensional construct and measures physical, social and psychological domains for quality of life for a person with epilepsy. This means that all the three domains have profound inter-relationship, where they influence the ways in which quality of life has been perceived amongst Iranian and British people. However, there was no difference in the mean scores of seizure severity functioning between these two countries. This suggests that seizure severity has been considered as clinical feature of epilepsy, so perhaps no matter where the person comes from, the nature of the illness should be the same regardless of nationality.

This study also adds support to the HRQOL model by introducing the interpretations of social comparison dimensions as social domains. This is because previously, the social domains of the model had mainly focused on marital functioning, leisure, other related social activities, social interactions and friendships (Baker et al., 1993). Yet, this study is unique as it has focused on the Theory of Social Comparison which can be applied to chronic illness (Festinger, 1954). In a way positive social comparison

(upward), can in fact be effective in terms of perceiving a better understanding of quality of life in living with epilepsy.

In addition, this study supports the biopsychosocial model of epilepsy (Engel, 1977; Elliot & Richardson, 2014), where in the treatment process of a chronic illness, healthcare professionals should address not only biological domain, they also should address psychological and social domains of patients' functioning. The theory suggests that the biomedical model is not sufficient on its own. Thus, it should be a related framework for social and psychological domains of illness. This model provides a full-print of an illness with adequate perspectives for healthcare professionals (Engel, 1977).

Applying to epilepsy, this study also contributes to the biopsychosocial model of epilepsy when presenting the interpretation of the social comparison process as a social domain for this model. This is because social domains of the model had mainly focused on education, employment, income and marital status (Suurmeijer et al., 2001; Elliot & Richardson, 2014). Though, the current study examined the Social Comparison Theory as the social domain of this model.

### **Supported Hypotheses**

With regard to Hypothesis 1, the social comparison dimensions affect the quality of life for people with epilepsy in Iran and the United Kingdom; none of the social comparison dimensions predicted perception for quality of life in the United Kingdom's study. This could mean that the interpretation of social comparison does not influence the ways in which quality of life has been perceived amongst the British samples. Therefore, this hypothesis was not supported for the United Kingdom's study. With regard to the Iranian study, Hypothesis 1 is partly supported. Hypothesis 2 stating that anxiety will have a negative effect on the perception of quality of life of people with epilepsy in Iran and the United Kingdom was not supported. This was because anxiety did not predict quality of life either in Iran or in the United Kingdom. Regarding Hypothesis 3 which stated that seizure severity will have a negative effect

on the perception for quality of life for people with epilepsy in Iran and the United Kingdom; seizure severity was found to predict quality of life for the United Kingdom's study. Therefore, it was not supported for the Iranian study. Hypothesis 4, which hypothesized that those with high self-esteem will perceive a better perception of quality of life in Iran and the United Kingdom, was supported in both countries.

### **Group Differences**

Looking at differences in perception of quality of life between Iran and the United Kingdom, it has become evident that the poorer self-esteem was reported in Iran than the United Kingdom's study. The interpretation of this finding can be attached with many social functioning burdens in living with epilepsy in Iran (Zamani et al., 2014; Maroufi et al., 2014). For example, Zamani and colleagues found that Iranian individuals with epilepsy have to face negative attitudes in society, such as associated stigma with epilepsy which lead people to have a misconception about this chronic illness (2014). The stigmatising nature of epilepsy may lead individuals to lose their social network (Jacoby, 2000; Baker, 2002; Baker et al., 2015). Factors, such as insufficient insurance support and lower levels of socioeconomic status could also affect the level of self-esteem (Hosseini et al., 2010). In addition, previous research found that epilepsy is associated with less educational achievement and lower rates of employment in Iran (Baker et al., 2005). This is probably because feeling different from others affects their social performance and they can lose their social values which results in decreased self-esteem.

It was found that individuals with epilepsy in Iran were more likely to perceive anxiety than those of the United Kingdom. Even though the unpredictable nature of epilepsy could result in a perceived anxiety (Jacoby et al., 2005; Baker et al., 2005; Beyenburg et al., 2005; Baker et al., 2013), the social differences should not be neglected (Baker 2002). Although there is insufficient research in Iran about epilepsy, Zamani et al. (2014), highlighted the social difficulties of living with epilepsy in Iran. It is possible that Iranian people, beyond their seizure impacts, perceive more anxiety due to inadequate financial support and unemployment rates amongst people with epilepsy in society. These factors may result in perceived anxiety more than in the United



Kingdom. This is because whilst Iran is considered a developing country, the United Kingdom is a well-known developed country and there are noticeable differences rooted in social diversities, such as health education, health services, and the cost of treatment which in turn can lead people to many psychological complications, such as anxiety, and a perceived poorer quality of life as a consequence.

In addition, it was found that people in Iran were more engaged in downward comparison than in the United Kingdom. This could mean that interpretation of downward social comparison whether positive or negative affects the ways in which quality of life was perceived amongst those Iranians with epilepsy. Looking at positive comparison (downward), it becomes evident that people with poorer self-esteem in Iran, were more likely to compare themselves to worse-off others for the purpose of self-enhancement (Stanton et al., 1999; Taylor, 1983; Dibb & Yardley, 2006). This finding supports the downward comparison theory (Wills, 1981), suggesting that people with lower self-esteem are more likely to compare themselves to unfortunate others, for self-evaluation. In addition, Bogart and Helgeson (2000), found support for positive comparison (downward), and stated that the more comparison to worse-off others the increased level of self-esteem was perceived amongst women with breast cancer. This may also support the Cognitive Adaptation Theory (Taylor, 1983); indicating that for the purpose of self-enhancement, individuals are more eager to engage in downward comparison.

Ultimately, a poorer perception of quality of life was perceived amongst those living with epilepsy in Iran in comparison to that of the United Kingdom. This may be associated with the type of lifestyle and socioeconomic status, medical costs (where they all have to pay for medications), in turn has led them to perceive a poorer quality of life (Zamani et al., 2014; Maroufi et al., 2014). In addition, psychosocial factors, such as improved psychological well-being and the healthcare system should not be neglected as they are important factors in maximising quality of life of Iranian people living with epilepsy (Hosseini et al., 2010). This is consistent with previous Iranian studies (Zamani et al., 2014; Rajabi et al., 2009), where unsatisfactory states of quality of life have been reported in Iran amongst individuals living with epilepsy. In general, decreased self-esteem, higher levels of anxiety and a poorer quality of life was found

amongst the Iranian samples more than in the United Kingdom's samples. This was confirmed by previous research in Iran (Rajabi et al., 2009); signifying that the lower perception of quality of life in Iran was associated with psychological difficulties, insufficient financial support, misconception about epilepsy and lower socioeconomic status all in turn led Iranian people to perceive a lower quality of life (Hosseini et al., 2010; Zamani et al., 2014). It is possible that lower levels of psychological well-being in society may add extra pressure to individuals' lives which in turn leads to a poor perception for quality of life.

## **7.9 Conclusion**

This study documents quality of life outcomes in people living with epilepsy in Iran and the United Kingdom. Findings show a significantly poorer quality of life in Iran in comparison to the United Kingdom. When looking at health related quality of life domains, it becomes evident that psychological domain (self-esteem) was found to be an important and significant predictor for quality of life for people living with epilepsy in both countries. This indicates that psychological well-being has a prominent influence on the perception of quality of life for people living with epilepsy. Whilst physical domain (seizure severity), was another main predictor of quality of life in the United Kingdom's study, social domain (social comparison), was an additional main predictor of quality of life in the Iranian study.

## CHAPTER 8: THE GENERAL DISCUSSION

### 8.1 Introduction

The main aim of the research presented in this thesis was centred on answering the research question, ‘Does social comparison influence the perception of quality of life amongst people with epilepsy living in Iran and United Kingdom?’ This has been achieved through the development of three studies which provided the main answer to the research question. This final chapter summarises the main findings of the first two qualitative studies and evaluates the hypotheses of the third study to determine whether or not they are supported. In order to do this, this chapter will review the most important findings from the three studies of this thesis; they will be discussed in accordance with the literature and previous findings. The qualitative and quantitative findings will be combined to triangulate outcomes in order that the results are jointly corroborated.

In addition, general implications of these results for epilepsy populations are presented. Limitations of the current research will be discussed, followed by the conclusion and research suggestion for future studies.

### 8.2 Summary of the Main Findings

#### 8.2.1 Chapter 5

The main objectives of the exploratory studies in the United Kingdom were to explore the life experience of people living with epilepsy, and to investigate coping strategies applied in this country.

#### **Experience of living with epilepsy in the United Kingdom**

Overall, the findings of first exploratory study in the United Kingdom appear to support the Social Comparison Theory as proposed by Festinger (1954). The theory indicates that individuals, when threatened and uncertain about their own circumstances, prefer to compare themselves with better-off others, which could result in negative effects as a consequence. In addition, the findings appear to support the

Identification/Contrast model (Buunk & Ybema, 1997); indicating that British people with epilepsy rather than identifying with better-off targets are contrasted with fortunate others, which, in turn, led to perceive negative effects. The findings are in line with previous research on social comparison and chronic illnesses, which argue that contrasting with a superior target led patients to be reminded of their own position in life and how bad they are doing in comparison to their target (Buunk et al., 2006 ; Arigo et al., 2014). The negative interpretation of upward comparison has been evident amongst cancer patients (Buunk et al., 1990). Consistent with this, similar studies have confirmed the negative effect of upward comparison in other chronic illnesses, such as cancer patients (Van der Zee et al., 2000), Meniere's disease (Dibb & Yardley, 2006), women with breast cancer (Bogart & Helgeson, 2000), Multiple Sclerosis (Dilorenzo et al., 2008) and cancer survivors (Brakel et al., 2012). However, no previous study in the United Kingdom explored negative social comparison interpretations (upward), in living with epilepsy as a neurological chronic illness.

Living with epilepsy may associate with uncertainty, psychological difficulties (Baker et al., 1997; Jacoby, 2000; Baker, 2002). Consistent with this, the first exploratory study in the United Kingdom showed psychological complications, such as; anxiety and fear were perceived amongst those living with epilepsy. This has a foundation on the unpredictability of an epileptic seizure (Jacoby et al., 2005; Gaitatzis et al., 2004; Baker et al., 2005; Ekinici, 2011; Baker et al., 2013). This could mean that individuals with epilepsy do not know when seizures will occur, in a way it has appeared that they felt they are waiting for the next seizure whilst they have just recovered from the previous one.

Social consequences should not be neglected. This study in line with previous research in the United Kingdom (Taylor et al., 2011); found that a small number of British people perceived stigma in society. Feeling stigmatised may have association with social ramifications, unemployment and social isolation as reported in previous studies (Suurmeijer et al., 2001; Livneh et al., 2001; Bishop & Allen, 2003; De Boer et al., 2008; Smith et al., 2009; Kerr et al., 2011).

In addition, this study, unexpectedly, found urinary incontinence to be a comorbidity of an epileptic seizure and led some participants to perceive anxiety afterwards. This

finding is in light of previous research that reported urinary incontinence as a comorbid condition of epilepsy (Télez-Zenteno et al., 2005). Much more is known about the clinical diagnosis of urinary incontinence (Dworetzky, et al., 2005; Timary et al., 2002; Brigo et al., 2013); yet, little is known about this somatic symptom from psychological perspective.

### **Coping strategies in the United Kingdom**

Looking at coping strategies in the United Kingdom, the second exploratory study found that British people appeared to use the problem-focused coping strategy as a mechanism in coping with their illness. This could mean that they perceived epilepsy as a controllable event, and as a result, were more likely to solve their problem practically, rather than emotionally (Folkman & Lazarus, 1980). The findings support the problem-focused coping theory; actively engaging in solving problem (Folkman & Lazarus, 1980). Consistent with this, the current study found that British participants with sufficient coping resources may perceive the stressor as less threatening; referring to one form of coping at a certain time. In addition, the findings were confirmed earlier by Folkman and Lazarus (1980); highlighting the importance of the problem-focused coping strategies in which people actively engage to obtain information to solve the problem (Kemp et al., 1999; Piazzini et al., 2007). This type of coping in epilepsy literature has been conceptualised as a task-oriented strategy (Livneh et al., 2001; Bautista et al., 2013). In addition, the problem-focused coping has a profound foundation on psychological well-being in epilepsy; the more perceiving the illness as a less threatening event, the better psychological well-being is perceived (Krakow et al., 1999; Oosterhuis, 1999; Goldstein et al., 2005; Westerhuis et al., 2011).

Previous studies showed that positive social comparison is associated with better adjustment amongst those living with Meniere's disease (Dibb & Yardley, 2006), women with breast cancer (Bogart & Helgeson, 2000; Van der Zee et al., 2000) and people with spinal cord injury (Dibb et al., 2013). Consistent with this, the coping study in the United Kingdom showed that British people appeared to use positive social comparison (downward), as a mechanism in coping with epilepsy, in particular, urinary incontinence. This could mean that instead of making negative comparison,

British people felt better adjusted after comparison to a worse-off target, as they felt dissimilar to unfortunate others. This supports the Identification/Contrast model (Buunk & Ybema, 1997); referring to do positive social comparison to unfortunate others which led to positive adjustment and perceived positive consequences. In addition, the findings build upon the work of Wills (1981), indicating that threat always leads to downward comparison, that is, there is comparison with less fortunate targets in order to learn how to cope in a positive way. It is known that downward positive comparison is associated with increased self-esteem (Wood et al., 1985; Wills, 1981), ego enhancement (Stanton et al., 1999), and self-enhancement (Taylor, 1983). The findings may support the Cognitive Adaptation Theory (Taylor, 1983), emphasised on self-enhancement as a process of adjustment to the threatening event. This is important to this study as Taylor (1983), believed that self-enhancement is achievable with downward positive comparison. Applying to epilepsy, British people who had urinary incontinence were engaged in positive comparison to worse-off others for self-enhancement. Dibb et al. (2013), suggested that downward positive comparison has the potential to inspire people in the context of living with chronic illness. However, this is a uniqueness of the study; as no study has highlighted positive social comparison (downward), as a coping strategy in living with epilepsy.

### 8.2.2 Chapter6

The main objectives of the exploratory studies in Iran were to explore the life experiences of people living with epilepsy, and to investigate coping strategies applied in this country.

#### **Experience of living with epilepsy in Iran**

Overall, the findings of the exploratory study in Iran support the Social Comparison Theory (Festinger, 1954). The model refers to the need for comparison in unclear circumstances. In particular, individuals when in threatening circumstances prefer to form a comparison with others in order to evaluate themselves (Gibbon et al., 2000; Bennenbroek et al., 2002; Brakel et al., 2012). This indicates that Iranians appeared to socially compare themselves to better-off others, and perceive negative feelings as

a consequence; due to feeling dissimilar to the target group (White et al., 2006; Dibb & Yardley, 2006). The findings also support the Identification/Contrast model (Buunk & Ybema, 1997). This could mean that Iranians with epilepsy rather than identifying with better-off targets are contrasted with fortunate others, which, in turn, led to perceived negative effects. The negative effect of social comparison has been perceived in different chronic illnesses; such as people with sickle cell disease (Wilson et al., 1997), Meniere's disease (Dibb & Yardley, 2006), cancer (Buunk et al., 1990; Bellizzi et al., 2006), multiple sclerosis (Hemphill, 1989; Dilorenzo et al., 2008) and spinal cord injury (Dibb et al., 2013). However, this is a first attempt to show the social comparison influences amongst people living with chronic illness in Iran, in particular epilepsy.

The unpredictable nature of a seizure may cause psychological difficulties (Baker, 2002; Jacoby et al., 2005; Baker et al., 2005; Ekinci, 2011; Baker et al., 2013). Consistent with this, this exploratory study in Iran found that individuals felt frightened and anxious as a consequence of an unpredictable seizure. They felt uncertain as they were not aware of seizure recurrence. This uncertainty (Stanton et al., 2007; Baker, 2002; Hills, 2007), and uncontrollability of an epileptic seizure (Baker, 2002; Gaitatzis et al., 2004; Jacoby et al., 2005; Baker et al., 2005; Ekinci, 2011; Baker et al., 2013) led them to develop anxiety. The prevalence of less psychological well-being in living with epilepsy has also been evident in previous European literature (Johnson et al., 2004; Goldstein & Harden, 2000). In regard to Iranian studies, although there is insufficient literature on epilepsy research in Iran, a recent study from Iran confirms the profound interaction between epilepsy and anxiety (Maroufi et al., 2014). Therefore, this study will contribute to the growing body of Iranian literature with filling the gap in this area.

In addition, a great number of Iranians appeared to be anxious as a consequence of passing urine. This highlights the profound association between incontinence and less psychological well-being, namely anxiety (Bogner et al., 2002; Stauber et al., 2007; Abrams et al., 2010; Sinclair & Ramsay, 2011), and depression (Molinuevo & Batista-Miranda, 2012). However, this issue has received little attention in epilepsy literature, from psychological perspective.

Social ramification and the effects of stigma have also been reported amongst Iranians with epilepsy. This is in line with previous Iranian literature (Vanzan & Paladin, 1992; Valizadeh et al., 2013) who revealed that epilepsy has been considered one of the most stigmatised illnesses in Iran. This may have a foundation on the traditional ‘taboo’ about epilepsy which led some individuals to have negative attitudes toward people with this chronic illness (Baker et al., 1997; Jacoby, 2000; Baker, 2002). Illness concealment has also reported; due to misconceptions about epilepsy (Hosseini et al., 2011). Associated stigma with epilepsy and misconceptions about this neurological illness are not exclusive to Iranian culture. Studies from Middle Eastern countries have also shown the stigmatising nature of epilepsy (Awad, & Sarkhoo, 2008; Muthaffar & Jan, 2014). Social discrimination, divorce and unemployment, have been reported in recent Iranian studies, which led patients to conceal their illness (Hosseini et al., 2010; Zamani et al., 2014). The psychosocial complications of living with epilepsy were resulted in financial difficulties (Heo et al., 2009). In line with this, a great number of Iranians experienced financial problems as a negative consequence of living with epilepsy. Hosseini et al. (2010) confirmed the serious financial problem of patients in Iran and stated that patients were eager to seek financial help from governmental institutions to cover the costs of their medication.

### **Coping strategies in Iran**

The second qualitative study in Iran showed that Iranians appeared to use more emotion-focused coping strategies as a mechanism for living with their illness. The findings support the emotion-focused coping theory (Folkman & Lazarus, 1980); indicating that Iranians were eager to deal with their circumstance more emotionally; rather than make practical changes (Livneh et al., 2001). Earlier Folkman and Lazarus (1980), suggested that if the stressor is perceived as an uncontrollable event, then an emotion-focused form of coping increases which, in turn, appears to be successful in terms of venting emotions and lowering distress (Roth & Cohen, 1986).

This could mean that Iranians perceived epilepsy as an uncontrollable event. Previous studies highlighted the emotion-focused coping as a strategy amongst those living with chronic illnesses (Folkman & Lazarus, 1985), in particular epilepsy (Oosterhuis, 1999;



Piazzini et al., 2007). A recent study from Iran supports emotion-focused coping as a mechanism amongst Iranian people with epilepsy (Hosseini et al., 2010). However, it should be noted that emotion-focused coping might be helpful at the beginning stages of the illness. Livneh et al. (2001), emphasized on this and stated that crying or venting emotion helps a person to adapt themselves to threatening circumstances. However, if it persists for longer; this type of coping may turn out to be a maladaptive strategy. This could lead to less psychological well-being and more psychological complications (Goldstein et al., 2005; Westerhuis et al., 2011), in particular depression (Stanton et al., 2000). The more venting of emotion, the less psychological well-being could be the outcome for Iranians living with epilepsy.

The significance of family function has been highlighted in an Iranian study amongst those living with epilepsy (Hosseini et al., 2010). The author argued that the more family care was perceived, the more that psychological well-being was reported. Consistent with this, the current study revealed the importance of family function and social support amongst Iranians living with epilepsy. Seeking social support has been previously reported as a positive mechanism in coping with threatening events (Folkman & Lazarus, 1988; Goldstein et al., 2005; Westerhuis et al., 2011; Bautista et al., 2013). The importance of religious coping as an active coping mechanism in epilepsy should not be neglected (Tedruss et al., 2013). In line with this, Iranians appeared to cope with their incontinence through their beliefs. This could mean that Iranians felt better adjusted when they empower themselves with their strong beliefs (Bautista et al., 2013). This is in line with a previous Iranian study (Hosseini et al., 2010), which supported religious beliefs as an active coping mechanism in living with epilepsy. This is because it empowered patients to accept their illness. The importance of religious coping with chronic illnesses has been previously shown in women with breast cancer (Thune-Boyle et al., 2006; Choumanova et al., 2006). It is known that religious coping as a strategy in living with chronic illness, may be associated with emotional support (Carver et al., 1989). Religious coping may have a foundation on being highly religious and spiritual in Iranian society, thus when diagnosed with a chronic illness; people are more likely to engage in religious activities in order to empower themselves. As they believe that their strong religious beliefs could rescue them.

### 8.2.3 Chapter 7

This chapter aimed at examining the discussion on the influencing factors for perception of quality of life in people living with epilepsy in the United Kingdom and Iran. This cross-sectional study presented the interpretation of social comparison and its influence on quality of life after controlling demographic characteristics, physical (seizure severity), and psychological factors (self-esteem and anxiety).

Overall, the findings support the Social Comparison Theory (Festinger, 1954), by examining this theory in epilepsy as a chronic illness. Positive social comparison (upward), was found to predict quality of life in Iran. This indicated that comparison with better-off others and feeling inspired and hopeful was associated with a better perception of quality of life amongst Iranian individuals. Hence, the first hypothesis was partly supported; signifying that upward identification comparison had a positive effect on the perception of quality of life for people with epilepsy in Iran. This also supports the Identification/Contrast model (Buunk & Ybema, 1997); indicating that if individuals felt similar to better-off targets and further believed that they could be like them too in future, then they would experience positive effects as result (Van der Zee et al., 1998; Dibb & Yardley, 2006). Consequently, considering some positive 'role models' for people with epilepsy in Iran, would help them to be inspired and optimistic about the future (Taylor & Dakof, 1988; Taylor & Lobel, 1989; Stanton et al., 1999; Dibb et al., 2013). Therefore, it can be argued that if Iranians seek affiliation with fortunate others, it may help them to perceive positive effects and experience a better quality of life as a consequence (Bennenbroek et al., 2002); and hence, better adjusted to their illness. It is known that engaging in upward positive comparison is associated with self-enhancement and self-improvement, as it provides individuals with required information (Wood et al., 1985; Blanton et al., 1999; Buunk et al., 2007). However, if the nature of the study was longitudinal, then examining the effect of social comparison on quality of life over time would have been possible, yet this study could not test for any causality.

Social comparison, however, does not seem to have any degree of influence on the perception of quality of life amongst the United Kingdom's participants; therefore,

Hypothesis 1 was not supported for the United Kingdom's study. This is because neither of the social comparison dimensions' interpretations could predict quality of life in the United Kingdom's study. This has implications for the interpretations of negative social comparisons (upward and downward), which were mediated by self-esteem. This suggests that high self-esteem can diminish the negative effect of comparison, after comparing with either better-off or worse-off targets (Gibbons & Gerrard, 1991; Dibb & Yardley, 2006). In other words, self-esteem moderated the relationship between the interpretations of social comparison dimensions and perceived quality of life amongst the United Kingdom's participants. Previously, Tennan et al. (2000) reported those with high self-esteem were more likely to engage in downward comparison. The mediation and moderation effect were not confined to the United Kingdom's study, this was because self-esteem, likewise, mediated the effect of upward contrast in Iran. This means that high self-esteem could moderate the perceived negative feelings after comparison to fortunate others. This is consistent with previous findings which found that with the positive effect of high self-esteem in social comparison dimensions, individuals are more likely to avoid negative interpretation of comparison, whether upward or downward (Buunk et al., 1990; Dibb & Yardley, 2006).

The more experience of a seizure, the more negative impact on perception for quality of life was perceived amongst British people. This finding, partly, supported Hypothesis 3 which predicted that high seizure severity will have a negative effect on quality of life amongst the participants in the United Kingdom. The findings are in line with previous research which highlighted the quality of life construct as an associated factor with seizure severity (Jacoby, 2000; Harden et al., 2007; Adebayo et al., 2014).

The most consistent variable that had a positive influence on perception of quality of life in both countries was self-esteem. This suggests that high self-esteem led the Iranians and British participants to perceive a better perception for their quality of life. This showed the importance of psychological domains in the perception of quality of life in Iran and the United Kingdom. This supported Hypothesis 4 which indicated that those with high self-esteem perceived a better quality of life. This is consistent

with European literature which highlighted that people with high self-esteem tend to perceive a better perception for quality of life (Suurmeijer et al., 2001; Taylor et al., 2011; Elliott & Richardson, 2014), and Iranian literature (Zamani et al., 2014). However, anxiety did not emerge as significant for the perception of quality of life either in Iran or in the United Kingdom. Hence, Hypothesis 2, which proposed that anxiety will have a negative effect on quality of life for people with epilepsy, was not supported. It is possible that anxiety did not affect the ways in which people perceived their quality of life.

### **8.3 Supporting the Quality of Life Models**

Evidence to support the models of this thesis can be found in the third cross-sectional study, where quality of life had a significant relationship with seizure severity, anxiety, self-esteem and social comparison dimensions. More specifically, seizure severity as a physical domain had a negative significant influence on perceived quality of life amongst British people. Self-esteem as a psychological domain positively influenced the quality of life both in Iran and the United Kingdom. In addition, positive social comparison (upward), as a social domain showed positive significant influence on the perception of quality of life amongst Iranian people with epilepsy.

Finally, the definition for quality of life in this thesis is the subjective perception for the impact of epilepsy on perceived quality of life, supported by examining the effects of multiple dimensions on those subjective aspects for quality of life, namely physical, psychological and social domains.

### **8.4 Supporting the Literature**

Overall, the current study supports previous research. The quality of life construct has been linked to seizure severity (Devinsky et al., 1999; Cramer et al., 2002; Harden et al., 2007; Adebayo et al., 2014), self-esteem (Collings, 1990; Suurmeijer et al., 2001;

Baker et al., 2005; Taylor et al., 2011), and anxiety (Jacoby, 2000; Johnson et al., 2004; Bazil, 2004; Tracy et al., 2007; Zeber et al., 2007), amongst epilepsy population. The findings of the current study have also demonstrated these variables to be associated with quality of life. Seizure severity has been linked to quality of life in epilepsy, in a way; experiencing severe seizures may decrease quality of life, especially when they facilitate the development of anxiety and social isolations (Harden et al., 2007). This leads to the worry of seizures which contribute to anxiety amongst people with intractable epilepsy (Harden et al., 2007; Adebayo et al., 2014). In addition, self-esteem may have an impact on quality of life amongst people with epilepsy (Suurmeijer et al., 2001) in that it predicts quality of life more than clinical status.

Anxiety has also been linked to quality of life in epilepsy which in turn is associated with reduced HRQOL (Johnson et al., 2004). In addition, poor self-esteem has been highlighted as important to the perception of quality of life in the biopsychosocial model of epilepsy (Suurmeijer et al., 2001), indicating that a decreased level of self-esteem was associated with a poorer perceived quality of life.

The biopsychosocial model proposed the framework for this study in which an illness can be understood in a combination of physical, psychological and social domains (Engel, 1977). According to the model, psychological and social domains explain the perception of quality of life more than physical domain. The results in this thesis show evidence for the biopsychosocial model, as psychological and social domains accounted for more variance than physical domains in the Iranian study. This also supports other studies such as Elliot and Richardson (2014), which also found the biopsychosocial model accounted for greater variance than the biomedical model. It was shown that people with epilepsy had more difficulties on psychological dimensions than physical ones (Elliot & Richardson, 2014). In addition, another study supporting the biopsychosocial model in epilepsy and stated that although seizure freedom can have a fundamental impact on the individual's life, still psychological effects should not be neglected (Lu & Elliott, 2012). Applying to the current study, this study has shown this collaboration of the three domains, namely seizure severity as a physical domain, self-esteem as a psychological domain, and social comparison

interpretations as social domains have been highlighted as important to the perception of quality of life amongst people with epilepsy in Iran and the United Kingdom. More specifically, it can be argued that experiencing the impact of seizure may affect Iranians more than the seizure itself; this is because psychological and social domains accounted for perception of quality of life more than physical domains in the Iranian study.

A Patient-Based Health-Related Quality of Life model in epilepsy (Baker et al., 1993), proposed the framework for this study to examine the profound interaction between the physical, social and psychological well-being of epilepsy. The model stated that in order to have a comprehensive view of an illness, the physical, psychological and social domains are required to be examined. This will help to understand the overall well-being on quality of life in epilepsy. The results in this thesis show evidence for the HRQOL model in epilepsy, as the physical and psychological domains accounted for quality of life amongst British people. This is in line with previous studies, such as Taylor et al. (2011), which also found support for the HRQOL model in epilepsy and argued that in order to have accurate epilepsy management the psychological and social functioning of a person should be taken into consideration. Taylor and colleagues further highlighted the significance of the psychosocial burden of living with epilepsy, such as anxiety and depression, and stated that more research is required to examine the predictors of HRQOL in epilepsy (2011). An earlier study by Cramer et al. (1998), confirmed the multidimensional concept for quality of life, and designed the questionnaire (QOLIE-31), to measure the HRQOL domains in epilepsy, which specifically covered emotional/psychological effects and medical/social effects. Applying to the present study; the quality of life was measured to see the influence of social domains after controlling physical and psychological domains. The result confirmed that seizure severity (physical domain), self-esteem (psychological domain), and positive social comparison dimensions (social domain) have complex interactions.

In the context of social comparison influences on epilepsy, the negative social comparison (upward), occurred amongst people with epilepsy in Iran and the United Kingdom, this may support the Identification/Contrast model (Buunk & Ybema, 1997); referring to feeling negative after comparison to fortunate others. In addition,

social comparison appeared to have a substantial role in the adjustment process to urinary incontinence for people with epilepsy whilst having a seizure. This also supports social comparison as an adjustment process to chronic illness (Taylor, 1983; Gibbons & Gerrard, 1991; Van der Zee et al., 2000; Bogart & Helgeson, 2000), and also supports Wills' (1981), theory of downward comparison, referring to the role of positive downward comparison. In addition, this may also support the Cognitive Adaptation Theory (Taylor, 1983); indicating that for the purpose of self-enhancement, individuals are engaged in downward comparison. Finally, social comparison was performed as an inspiration and motivation to have better understanding for quality of life in living with epilepsy. This was supported by Taylor & Lobel (1989), who purposed that people strive to be seen to be better than their current circumstances. It also supported evidence of searching for affiliation through upward positive comparison, for self-improvement (Wood et al., 1985; Blanton et al., 1999; Stanton et al., 1999; Buunk et al., 2007; Dibb et al., 2013). In addition, the findings support the previous research that the better perception of quality of life was associated with downward contrast and upward identification (Van der Zee et al., 2000; Dibb & Yardley, 2006). This implies that individuals with epilepsy in Iran after comparison to some positive role models, can affiliate themselves with their more fortunate target, and be inspired and hopeful that they can be like that target in the near future. This supports other studies which show the positive influence of upward comparison amongst cancer patients (Bennenbroek et al., 2002; Brakel et al., 2012). However, the interpretation of social comparison was not tested over time. Since the upward comparison was positively significant, it can be speculated that it will have a direct effect on perceived quality of life over time amongst Iranians living with epilepsy.

However, it should be acknowledged that although this thesis has a foundation on the Social Comparison Theory, the rationale for supporting the quality of life models, such as the Biopsychosocial model, has been grounded on the definition of quality of life which is given in this thesis. Since the subjective perception of quality of life is examined, the physical and psychological factors should be taken into consideration in perception of quality of life. Therefore, A Patient-Based Health-Related Quality of Life model in epilepsy (Baker et al., 1993) and the Biopsychosocial model (Engel,

1977) can support this definition as the models cover three main domains of quality of life amongst people with epilepsy, namely, physical, psychological and social, where all these domains have strong interactions. Evidence that these models have been supported could be found in significant association between quality of life and the seizure severity, the self-esteem and the social comparison dimensions. In the current study, support for the models would consist of evidence that the physical factor has an impact on quality of life, that there is a significant effect of self-esteem on quality of life, and a significant association between social comparison dimensions and quality of life. Evidence to support the models can be found in the cross-sectional data where the seizure severity variable had a significant impact on perceived quality of life. Self-esteem influenced perceived quality of life, and positive social comparison (upward) had a significant influence on perceived quality of life.

### **8.5 What the Findings Mean for Individuals with Epilepsy in Iran and the United Kingdom?**

The result of this study shows that Iranian people were more likely to follow some positive role models to be inspired and motivated to be like those fortunate others and hence, achieve a better understanding of their illness. This is supported by research amongst cancer patients (Bennenbroek et al., 2002; Brakel et al., 2012). They found that patients mostly tended to receive information from those who were in better situations; indicating they were seeking affiliation with others who are more fortunate. Applying this to epilepsy, it could mean that Iranian people with epilepsy may affiliate with upward targets, which helps them have a better understanding of their life. In addition, it was shown that those with high self-esteem perceive a better quality of life in Iran and the United Kingdom. Hence, those with a lower level of self-esteem perceive a poorer quality of life, and they may need further help. The positive interpretation found with comparison to others who are more fortunate may help Iranian and British individuals improve their self-esteem (Wood et al., 1985). This is because self-esteem was shown to have an inverse relationship with negative social comparison (upward and downward). In addition, self-esteem was associated with positive social comparison (downward), in the United Kingdom. This could imply



that, the higher the level of self-esteem and the more positive the social comparison, the better the perception for quality of life the British people will have. This could also help British people with epilepsy adjust better to their illness (Van der Zee et al., 2000).

This is in line with a study by Dibb and Yardley (2006), amongst people with Meniere disease indicating that patients with high self-esteem were more likely to perceive better quality of life, and adjust to their illness. In addition, those who engage in negative upward comparisons (as discussed in Study 1), may be required to improve their sense of coherence and maximise their control over that illness. Instead of making negative evaluations of themselves with others who are more fortunate, they can make positive self-assessments of themselves and achieve a better understanding. This is because feeling dissimilar with those who are better-off may result in depression and frustration over time (Taylor et al., 1983; Arigo et al., 2014).

In addition, this study found that those experiencing severe seizures perceived a poorer quality of life in the United Kingdom. This could mean that the more severe a seizure, the higher the level of anxiety, and social dysfunctions may perceive amongst individuals with epilepsy (Jacoby, 2000; Harden et al., 2007). This is because anxiety was positively associated with seizure severity both amongst Iranians and British people. Therefore, if the illness is managed, then people may have a reduced feeling of anxiety and hence perceive a better quality of life. This is supported by previous studies (Adebayo et al., 2014), which concluded that seizure reduction will help to improve a patient's quality of life. In addition the results show that seizure severity was positively associated with negative social comparison (upward and downward), both in Iran and the United Kingdom. This could mean that the more severity of a seizure may lead to negative feelings after comparison to others who are more fortunate. Also the more seizures are experienced by an individual the more they may experience negative feelings if they compare themselves with a worse-off target. Therefore, inability in seizure management may lead British people and Iranians with epilepsy to perceive a poorer quality of life.

The findings suggest that it is essential to manage the severity of a seizure, as it may lead to anxiety (Adebayo et al., 2014). Feeling of anxiety may provoke negative

comparison with someone who is better-off; and interpret this negatively, such as being jealous of someone who could drive or have their own autonomy. This study also suggests improving self-esteem as it can aid a person with epilepsy to do more positive comparisons, and interpret this positively (Dibb & Yardley, 2006). This in turn may lead to a better perception for quality of life.

This study also revealed that in Iran urinary incontinence was associated with poor a perception of quality of life. It can be suggested that Iranian people with epilepsy may need further assistance such as a psychological consultation, in order to adapt themselves to their incontinence as a part of their seizures. Some practical techniques can also be suggested for Iranian people with epilepsy who are incontinent; they may use contaminant devises such as pads whilst having a seizure. This could help them to better adjust to their incontinence in public, and may reduce their anxiety. All this help may result in having a better perception of quality of life for Iranian and British people living with epilepsy.

## **8.6 Triangulation**

This mixed-method study integrates qualitative and quantitative data amongst people with epilepsy from Iran and the United Kingdom. Although, previous, studies have used qualitative methods to explore life experiences, this study is novel as no prior studies have used a mixed-method approach to achieve input from individuals with epilepsy in two different countries.

The qualitative findings highlight the significance of considering peoples' physical, psychological, and social experiences when examining the subjective perception for quality of life. The quantitative approach allows an understanding of the relation between the variables. Quantitative findings are largely complementary of the qualitative outcomes and illustrate the importance of the perceived social and psychological factors for perceiving a better quality of life.

The themes in the qualitative data reflect the perceived challenges of those people living with epilepsy. The upward negative comparison indicates that people due to illness restrictions, and social barriers, continuously compared themselves to fortunate others and perceived negative feelings as a consequence. Participants in both countries indeed socially compared themselves to others who were more fortunate which resulted in feeling disappointed. Then, in the third quantitative study, the examination of social comparison in the larger population confirmed that in fact there was a negative association between negative comparison (upward), and the perception of quality of life. It can be said that triangulation occurred as both qualitative and quantitative results show that Iranians and British individuals with epilepsy who were engaged in upward negative comparison and perceived negative consequences, had a poorer perception of quality of life.

Similarly seizure impact, as a theme, suggests that due to the unpredictable nature of epilepsy, people may perceive psychological difficulties, such as anxiety and fear. Individuals in both countries appeared to perceive anxiety due to experiencing an epileptic seizure. This is because the unpredictable nature of epilepsy led participants to feel anxious as they did not know where or when they would have a seizure. Then statistically it was shown that those who experienced more seizures perceived anxiety. It can be said that triangulation occurred, as the results in both qualitative and quantitative studies support each other; in a way amongst those Iranian and British individuals who experienced more seizure, appeared to perceive anxiety. Therefore seizure management should be taken into consideration. It can be concluded that the less a seizure is experienced, the more psychological well-being will be perceived. In addition, downward positive comparison appeared as a coping mechanism amongst those living with epilepsy in the UK. Then, the examination of the social comparison dimensions, statistically, showed that engaging in positive comparison to worse-off others was associated with the better perception of quality of life. It can be argued that triangulation occurred, this is because both qualitative and quantitative results showed those British people who did positive comparison to unfortunate others, could adjust well and perceived a better perception of quality of life.

## 8.7 Implications of the Research

This study contributes to the growing body of literature by providing prominent information about the role of social comparison and its influence on the perception of quality of life of people living with epilepsy in Iran and the United Kingdom. The present research explored a number of highly important concerns for people living with epilepsy in the two countries. The issues mainly addressed were negative social comparison (upward), anxiety and urinary incontinence. In particular, it was noted that regardless of the country, living with a chronic illness can be debilitating and that it may lead a person experiencing negative psychological distress, such as anxiety. It can be suggested that using the Social Comparison Theory as a foundation for understanding living with epilepsy has important implications for self-evaluation, in comparison to other individuals living with or without epilepsy. Therefore, this study highlighted the Identification/Contrast model (Buunk & Ybema, 1997), which assessed the interpretation of social comparison dimensions in chronic illnesses, such as epilepsy. It provided appropriate information for the social comparison process for the epilepsy population in two different countries. Obtaining such information would help to understand how people with epilepsy experience different social circumstances. This information will also help to replace negative cognitive interpretation with positive cognitive interpretations of social comparison as suggested by Van der Zee et al. (2000). It is possible that ‘counting blessings’ could be helpful for those who made negative social comparison in this respect, cognitively, instead of feeling down in comparison to fortunate others. They can still replace this feeling by putting their thoughts into a positive perspective. This could help them to judge themselves positively, and feel pleased as they can count their blessings that many others, even fortunate ones, may not have.

This study provided more evidence on coping dimensions and the adaptation process to epilepsy. It has explored different coping strategies in two diverse countries. A wide range of coping strategies; the downward comparison (positive), the problem-focused coping, the emotion-focused coping and the religious coping strategies have been employed by the participants to combat the potential stress linked to their epilepsy. This study suggests that comparison with worse-off targets often resulted in

participants feeling better about living with epilepsy; especially those who were incontinent. This can be applied to the coping and adaptation literature for social comparison (Taylor & Lobel, 1989), which proposed that people are more likely to engage in a downward comparison when they are under threat, as it induces self-enhancement. This could be implemented to an individual's difference in coping strategies, such as self-esteem as recommended by Bogart and Helgeson (2000). This study suggests that positive downward comparison appears to have positive implications for self-esteem.

The findings of the current study suggests that it might be helpful if therapy and treatment programs for people with epilepsy can emphasise different coping strategies as a way of treatment, which in turn may highlight achieving and learning different problem solving coping strategies. Learning coping skills can be considered as a psychosocial adaptation to epilepsy, since acquisition of coping strategies could be implemented in assisting people with epilepsy to achieve their individual aims, such as controlling seizures, achieving social targets as well as socialising and being able to live a better quality of life. The researcher speculates that learning coping strategies can also help individuals with epilepsy control their stresses which are triggered by 'negative' family functions, such as, being overprotected by parents. Epileptologist and neurologists may choose to consider the various coping strategies when assessing their patients, as these strategies can offer different perspectives on how individuals with epilepsy may approach these diverse stressors in their life. This is in line with Westerhuis et al. (2011), suggestions referred to patients, where they need to be encouraged to develop their coping skills; since constructive coping strategies will maximise their adaptation to epilepsy.

This study provides more evidence for seeking affiliation with upward targets which appeared to be helpful for those with epilepsy in Iran. In this respect, they can follow 'positive role models' as it will inspire them to be optimistic about the future if they feel similar to the role model or aim to be like them in the near future. They will have a better understanding of their life, and hence, improve their quality of life. In addition, they can acquire information on coping dimensions to see how fortunate others dealt with their illness. This action can be associated with previous research

(Bennenbroek et al., 2002), which showed that comparison with others who are better off and coping well with their cancer, and receiving information from them was inspiring for patients.

This research also reinforces the case for establishing supportive charities for individuals with epilepsy in Iran. Such charities in the United Kingdom provide support to members in the form of monthly magazines about their illness, monthly panel conferences and additional medical information. This support contributes to establish the British participants' perception of their illness as controllable, as they felt there was always someone to provide them with enough information. These supportive charities may also provide peer-discussion as an opportunity for chronically ill patients. This can be considered as an intervention that may boost quality of life amongst those who are taking part in these discussions, as suggested by Bogart and Helgeson (2000). The researcher speculates that it would certainly be valuable for epilepsy patients in Iran to be provided with social comparison information. However, it should be noted that some people are hesitant to receive information about other chronically ill people. This can be linked to Wood et al. (1985), statement which highlighted the importance of self-esteem in the comparison process. Therefore, any intervention required is to be twofold; psychological (a way in which self-esteem can be increased), and social process directions. Given the research findings, there are possible areas for future research and examination. Establishing supportive charities for people with epilepsy in Iran also is worthy of seeing positive examples of how other people with epilepsy cope with their illness. This would help them to see how fellow patients deal with their epilepsy. In turn, this may lead people to increase their self-esteem (Wills, 1981), and accordingly perceive a better quality of life.

This study also indicated that British people with epilepsy appeared to be better equipped and could adjust themselves better than Iranian people who did not have access to financial resources. This could offer some guidelines to Iranian healthcare professionals to provide adequate funding opportunities for chronically ill patients, such as, people with epilepsy. This could be done by running a specific financial plan for the costs for medication, MRI and relative scans. This would be helpful for the

Iranian Epilepsy Society as previous research in Iran (Hosseini et al., 2010), highlighted the importance of organisational and governmental assistance for the population with epilepsy, as patients have been demanding this support in Iran.

### *8.7.1 Psychological Implications*

This study suggests that urinary incontinence may have an adverse psychological impact on people with epilepsy, as it was reported amongst Iranian and British people. This information could be implemented to promote educational programmes for health psychologists in Iran to help people familiarise themselves with this comorbid condition, and improve their knowledge in this area. Individuals must be educated on a wider range in order to know more about this somatic symptom and its impact on patients' lives. This could be achieved by healthcare professionals providing people with the required resources, such as free pads, similar to the United Kingdom's healthcare system. This could empower people with epilepsy in Iran to live an active life and reduce their associated psychological distress, such as, perceived anxiety due to passing urine in public. These suggestions could be implemented in educational intervention as recommended by Ramaratnam et al. (2005), which was found to be helpful in terms of improving an individual's knowledge of epilepsy. This may contribute to the growing body of knowledge in epilepsy, that is, how passing urine can be managed with psychological intervention.

### *8.7.2 Clinical Implications*

This study suggested more evidence on the negative impact of seizure severity on the perceived quality of life amongst the people in the United Kingdom. This suggests that seizure reduction should be considered as one of the main priorities in clinical trials amongst people with epilepsy in the United Kingdom. This is because seizure severity can promote anxiety as suggested by Harden et al. (2007). Therefore, this variable should be taken into account amongst neurologists as the more severe the

seizure that is experienced, the higher levels of anxiety that may be perceived. This information is also important for healthcare practitioners and clinicians. This is because evidence suggests that there should be extra effort in order to have a better understanding of the patients' quality of life in living with epilepsy, since seizure severity, as a physical domain negatively predicts quality of life in the United Kingdom.

The clinical intervention for urinary incontinence should not be neglected since to date, it has received only medical attention in epilepsy (Brigo et al., 2013). The present study suggested that urinary incontinence is an associated factor to an epileptic seizure in both countries, which often resulted in perceived anxiety. Previous studies suggested that multidisciplinary intervention should be taken into account as an intervention for urinary incontinence (Molinuevo & Batista-Miranda, 2012). They highlighted that clinical intervention should combine with psychological ones, amongst those with emotional distress in order to achieve a better health outcome.

Taken together, the current study aimed at providing important knowledge about epilepsy by identifying the main concerns of those people living with this neurological illness. Consequently, this information is useful so that people with epilepsy in Iran and the United Kingdom may receive the best possible treatment and psychological care from health professionals and their care givers.

## **8.8 Strengths and Limitations**

This study considered a wide range of participants living with epilepsy for a varied number of years. Previous research on epilepsy has mostly focused on other related factors without looking at the differences of diverse backgrounds. In addition, previous studies were either qualitative or quantitative. This was the first attempt to use a mixed-method approach in this field, and bring both qualitative and quantitative approaches together. This study can contribute towards that knowledge and thereby help in improving their life circumstances; as this is the first attempt to examine the Social Comparison Theory in epilepsy and to understand the illness from a self-evaluation perspective. In addition, unexpectedly, urinary incontinence was found to



be an issue amongst those living with epilepsy. Although this somatic symptom is not a psychological construct, the thoughts and feelings that may be triggered by urinary incontinence are psychological, which have been discussed in this thesis. In the study, participants had the opportunity to express their feelings and experiences freely.

However, the important limitation of this research lies in the sample size. Obtaining ethical approval from the NHS was time consuming and posed great difficulty for the researcher. Consequently, with respect to the qualitative studies, only 20 people within the United Kingdom could be accessed through supportive charities. Meanwhile in order to have matched groups of people in the study, the researcher aimed to find 20 people from Iran. Since the current study was conducted in particular areas of the countries, the findings could not be generalised to the larger population who may not have access to hospitals or supportive charities. Although the United Kingdom's study was conducted with the help of 'Epilepsy Research UK' and 'Epilepsy Action' located in London and Leeds, respectively; they have members all around the United Kingdom. Likewise, the Iranian study was conducted in the Neurological Hospital in Tabriz, North West of Iran. Although the researcher interviewed some people who were admitted in hospital, some participants were originally from the capital city and North East of Iran, hence, in this study there has been care to avoid over-generalisation of the results.

In addition, direction of correlations between psychological variables (self-esteem and anxiety), and urinary incontinence were, unexpectedly, different in the United Kingdom. However, it could be speculated that in Iran the pathway is from urinary incontinence to self-esteem, whereas in the United Kingdom the causal path might be from self-esteem and anxiety to urinary incontinence.

Given the researcher was not British and she was not familiar with British culture, cultural sensitivity was in mind during all the interviews; and she was mindful on her own position. With regard to the Iranian study, she was aware of not interviewing on religious occasions, namely, Martyrdom of Holy Imams and Ramadan. In order to limit influence, no biased questions, or leading questions were asked during the interviews both in Iran and in the United Kingdom.

Another limitation of this research was that it was cross-sectional. A longitudinal study would have been more suitable however, as an international student; the researcher was subjected to finish within three academic years based on student visa requirements. Since the nature of the longitudinal study was long and over time, it was a concern that the researcher would not finish her study by the provided deadline. Therefore, this study could not provide any causal relationships between variables. The role of interpretation on social comparison may therefore have an effect on ways in which people with epilepsy perceive their life over time, as found amongst patients with Meniere's disease (Dibb & Yardley, 2006).

## **8.9 Conclusions**

Finally, this is a mixed-method study aimed at examining the role of social comparison in the perception of quality of life amongst people with epilepsy in Iran and the United Kingdom. This thesis is a noticeable addition to the field as the study is unique. Firstly the Social Comparison Theory has been examined on epilepsy as a chronic illness. Secondly it was a mixed-method approach, which has been carried out between Iran and the United Kingdom. This helps to understand how social comparison is interpreted in two different countries. To date there was no comparison of the differences or similarities of people living with epilepsy from Iran and the United Kingdom. This distinction allowed the researcher to investigate more in this area between the two aforementioned countries, using qualitative and quantitative approaches and integrate the outcomes to have a better understanding of experiences. Thirdly, it is the only study that has explored coping strategies in epilepsy between Iran and the United Kingdom, specifically investigating the coping dimensions and adaptation process on urinary incontinence. After understanding the role of social comparison in the first study, a quantitative approach was taken to examine the true effect of social comparison on perceived quality of life amongst people with epilepsy in Iran and the United Kingdom. Quality of life was assessed in order to establish what factors could influence quality of life in these two countries.

Although coping strategies and quality of life for these populations were not tested statistically, it can be speculated that those who used problem-focused coping may have a better understanding of their quality of life in comparison to those who relied on emotion-focused coping strategies over time. This is because emotion-focused coping in the earlier stages of diagnosis might be helpful but may be maladaptive if prolonged (Lazarus, Folkman, 1980; Stanton et al., 2000).

This thesis provides a context in which we can understand epilepsy from a psychological perspective, rather than solidly a medical phenomenon. This thesis found that epilepsy, as a neurological illness, is attached to many social and psychological consequences such as perceived anxiety due to the unpredictable nature of a seizure (Ekinici, 2011; Baker et al., 2013), the effect of stigma (Taylor, et al., 2011; Valizadeh et al., 2013), social exclusion and unemployment (De Boer et al., 2008), and overprotection, lack of independency/autonomy (Livneh et al., 2001; Kerr et al., 2011). In general, this thesis enhances the knowledge about epilepsy amongst individuals to know how they manage their life with this chronic illness. Further, this study provides insight to the psychological burden of epilepsy, which in turn could add more into the medical aspect of epilepsy.

This research suggested that upward identification had a positive impact on perception of quality of life amongst Iranian people; those with high self-esteem perceived a better quality of life in both Iran and the United Kingdom, and high seizure severity had a negative impact on the perception of quality of life amongst British people. Since seizure severity had a negative impact on the quality of life amongst the United Kingdom's sample, it is necessary to identify those factors that can cause an individual to develop more seizures in future studies. This would help people with epilepsy in the United Kingdom to understand what can help them to reduce seizure severity, which then could lead them to perceive a better quality of life as a result. In addition, as the interpretation of positive social comparison (upward), positively predicted quality of life amongst the Iranian samples, future research could benefit from examining the impact of this positive interpretation whether it is helpful, not just for people living with epilepsy, but also for those who usually compare themselves with others in Iran.

Although this research was a good foundation for understanding the experiences of living with epilepsy for Iranian and British people, it would be interesting if future research looked at this illness from a longitudinal perspective. This will provide more opportunity over time to examine the profound effects of social comparison, psychological and physical domains on quality of life amongst people with epilepsy, and the causal relationship of the variables. In addition, since this research took a health psychological perspective, it would be interesting to investigate the cultural and ethnic differences within these countries to see how cultural diversities with different ethnic backgrounds can affect people's perception of quality of life. Also, future studies could address how parents or care givers perceived their life with having a child/partner with epilepsy. This is important as social support was reported in this study, where participants felt satisfied in terms of receiving support from either their parents or partners. In addition, the explanation of a causal pathway between psychological variables and urinary incontinence amongst the United Kingdom's correlation was speculative; therefore, future research directions could focus on a causal pathway between psychological variables (self-esteem and anxiety), and urinary incontinence; in a way longitudinal research could address this issue.

In conclusion, the overall quality of life for people with epilepsy should be a main focus of neurologist and general practitioners in Iran and the United Kingdom. Knowledge of this thesis is aimed at helping to determine the social comparison influences (both in a positive way and in a negative way), in people living with epilepsy. It is also hoped that the early diagnosis of epilepsy and associated psychological factors, would assist patients and reassure them in having a better understanding of their life with epilepsy. Psychological and clinical interventions, as suggested in this thesis, could help those with comorbid conditions to live in the best possible way so as to improve their quality of life. This mixed-method study provides a foundation on the social comparison influences on epilepsy, and it is novel as it adds to what we understand about social comparison in neurological illness.

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## Appendices

**Appendix A: Research Ethics Approval from Brunel University London**  
**(Study 1)**

Name of Applicant at Brunel University (please print): Aisan Ghaemian Oskouei

Signature of Applicant at Brunel University: \_\_\_\_\_  


Date: 10/04/2012

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This request for expedited review has been:  **Approved** (no additional ethics form is necessary)  
 **Declined** (full University ethics form is necessary)

Signature of PsyREC Officer: \_\_\_\_\_  


Date: \_\_\_\_\_  
Apr. 16, 2012

**Appendix B: Research Ethics Approval from Brunel University London**  
**(Study 2 & 3)**

Name of Applicant at Brunel University (please print): AJSAN GHAEMIAN OSKOUJ

Signature of Applicant at Brunel University: \_\_\_\_\_  


Date: 12.09.2013

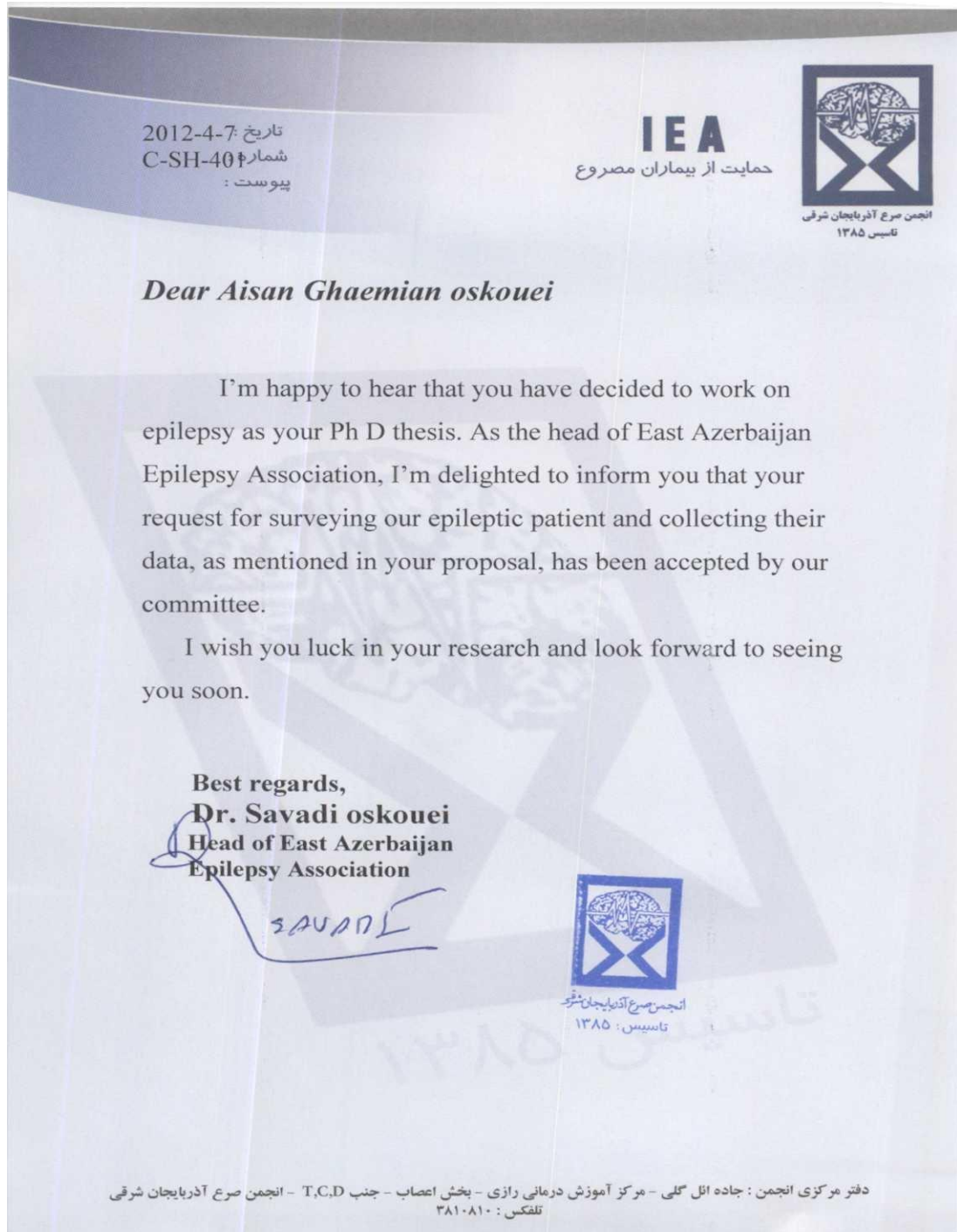
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This request for expedited review has been:  **Approved** (no additional ethics form is necessary)  
 **Declined** (full University ethics form is necessary)

Signature of PsyREC Officer: \_\_\_\_\_  


Date: 18-09-2013

## Appendix C: Permission from the Head of East Azerbaijan, Iran Epilepsy Association



## Appendix D: Agreement letter from Epilepsy Action, society

“Dear Aisan

Thank you for the copy of your ethics approval, and for clarifying details. I will draft something for the website, so we can link from social media. It will need to go through QA process, so it is likely to be next week before we can post information. I will let you know when it is living. I think the best thing to do is advertise for people in the South East, but say you would be interested to hear from people living elsewhere. We don't have any premises in London, so you will need to consider where you will carry out the interviews. If you would like us to advertise in Epilepsy Today, I will need the information by 20 September. This issue will be posted out to members in mid-November. Are you intending to have an online questionnaire? If so, we can host a link for you.

Best regards

Margaret Rawnsley [mrawnsley@epilepsy.org.uk](mailto:mrawnsley@epilepsy.org.uk)”

**Appendix E: Consent form and Debriefing form for British and Iranian participants (Study 1)**

**INFORMED CONSENT SHEET**

Living with Epilepsy

The Department of Psychology at Brunel University requires that all persons who participate in psychology studies give their written consent to do so. Please read the following and sign it if you agree with what it says.

I freely and voluntarily consent to be a participant in the research project entitled "Living with epilepsy" to be conducted at Brunel University, with Aisan Ghaemian Oskouei as principal investigator. The broad goal of this research program is to explore (what factors do people with epilepsy think are important to their quality of life) specifically; I have been told that I will be asked to meet with Aisan and talk about living with epilepsy , what helps and what doesn't .The conversation should take no longer than one hour.

I have been told that my responses will be kept strictly confidential. I also understand that if at any time during the session I feel unable or unwilling to continue, I am free to leave without negative consequences. That is, my participation in this study is completely voluntary, and I may withdraw from this study at any time. My withdrawal would not result in any penalty, academic or otherwise. My name will not be linked with the research materials, as the researchers are interested in investigating experience of people with epilepsy in general -- not any particular individual's idea in particular. I have been given the opportunity to ask questions regarding the procedure, and my questions have been answered to my satisfaction. I have been informed that if I have any general questions about this project, or ethical issues relating to the project, I should feel free to contact Aisan Ghaemian Oskouei at Aisan .Ghaemianoskouei@brunel.ac.uk. If I have any concerns or complaints regarding the way in which the research is or has been conducted I may contact one of the Co-Chairs of the Psychology Research Ethics Committee, Professor Taeko Wydell at [taeko.wydell@brunel.ac.uk](mailto:taeko.wydell@brunel.ac.uk) or Dr Tara Marshall at [tara.marshall@brunel.ac.uk](mailto:tara.marshall@brunel.ac.uk).

I have read and understand the above and consent to participate in this study. My signature is not a waiver of any legal rights. Furthermore, I understand that I will be able to keep a copy of the informed consent form for my records.

Participant's Signature	Please Print	Date
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I have explained and defined in detail the research procedure in which the above-named has consented to participate. Furthermore, I will retain one copy of the informed consent form for my records.

Principal Investigator Signature	Please Print
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## DEBRIEFING FORM

Living with epilepsy

In this study I'm interested in exploring what it is like living with epilepsy, what helps and what hinders quality of life for people with epilepsy.

The following studies might be of interest to you:

1. Chadwick & Usiskin (1992). Living with epilepsy. *Optima*.
2. Epilepsy society .org.uk

*Once again, thank you for taking part in this study*

**Consent form and Debriefing form for Iranian participants (Study 1)**

**برگه رضایت داوطلبانه**

**زندگی با صرع**

افرادی که در تحقیقات روانشناسی دپارتمان روانشناسی دانشگاه بروئل شرکت می نمایند، ملزم به اعلام رضایت کتبی خود نسبت به این انجام کار می باشند. لطفاً متن زیر را مطالعه کرده و در صورت توافق آن را امضا نمایید.

اینجانب رضایت داوطلبانه خود را نسبت به شرکت در پروژه تحقیقاتی با عنوان "زندگی با صرع" که در دانشگاه بروئل و توسط آیسان قائمیان اسکویی به عنوان محقق اصلی برگزار می گردد، اعلام می دارم. هدف کلی از این برنامه تحقیقاتی بررسی (تجربه زندگی با بیماری صرع می باشد).

اینجانب آگاه هستم که از من خواسته خواهد شد تا با آیسان ملاقات کرده و در مورد تجربه زندگی با بیماری صرع و اینکه چه چیزهایی موجب سهولت آن شده و چیزهایی نه، صحبت نمایم. این مکالمه بیشتر از یک ساعت به طول نمی انجامد

اینجانب آگاه هستم که پاسخ هایم به طور حتم محرمانه خواهد ماند. همچنین آگاه هستم چنانچه هر زمان در طول جلسه، احساس نمایم دیگر قادر به ادامه کار نبوده و یا تمایلی به آن ندارم، می توانم جلسه را بدون هیچ پیامد منفی ترک نمایم. بر این اساس، شرکت من در تحقیق، کاملاً داوطلبانه بوده و هر زمان می توانم از شرکت در آن انصراف دهم. انصراف من منجر به هیچ گونه جریمه ای اعم از آکادمیک و یا غیره نخواهد شد. نام من با مواد تحقیق مرتبط نخواهد شد، چرا که محققان به دنبال تحقیق و بررسی در زمینه (کیفیت زندگی بیماران مبتلا به صرع) به طور کل بوده و نه بررسی نظرات فردی اشخاص. این فرصت به من داده شد تا سئوالات خود را در رابطه با فرایند تحقیق مطرح نمایم و این سوالات به صورت قابل قبولی پاسخ داده شد. اینجانب آگاه هستم در صورت داشتن هرگونه سؤال در رابطه با پروژه و یا مسائل اخلاقی مربوط به آن، می توانم به راحتی آن را با آیسان در میان گذارم. همچنین در صورت وجود هرگونه نگرانی و یا شکایت در رابطه با نحوه اجرای تحقیق می توانم با یکی از مسئولان کمیته اخلاق در تحقیقات روانشناسی تماس برقرار کنم. Professor Taeko Wydell at [taeko.wydell@brunel.ac.uk](mailto:taeko.wydell@brunel.ac.uk) or Dr Tara Marshall at [tara.marshall@brunel.ac.uk](mailto:tara.marshall@brunel.ac.uk).

اینجانب مطالب بالا را خوانده و متوجه شده و رضایت خود را نسبت به شرکت در این تحقیق اعلام می دارم. امضای اینجانب به معنای چشم پوشی از حقوق خود نمی باشد. به علاوه، آگاه هستم که می توانم یک کپی از این رضایت نامه را نزد خود نگاه دارم.

شرکت امضاء کننده تاریخ

امضاء محقق تاریخ

## DEBRIEFING FORM

فرم گزارشگیری

در این مطالعه من علاقمند به جستجو آنچه مبتلا به صرع زندگی است هستم.

مطالعات زیر ممکن است مورد علاقه شما باشد:

از بیماری صرع بیشتر بدانید - مجله زندگی و سلامتی و سرگرمی

<http://magazine.a222.org/epilepsy/>

اطلاعات کتاب: زندگی با صرع "اثر زخمی در سر، نشانه‌ای از صرع"

بار دیگر، با تشکر از شما برای شرکت در این مطالعه

## Appendix F: Information sheet for British and Iranian participants

### **Participant information sheet**

My name is Aisan and I am a student at Brunel University. I'm carrying out some research to understand the experience of living with epilepsy.

I am inviting people with epilepsy to participate in this study. Persons interested in taking part with meet with me, Aisan Ghaemian Oskouei, at a time and place convenient to you to have a chat about your experience of living with epilepsy. Before you decide to take part in this study it is important for you to be familiar with the structure of this study. Please read the following information carefully.

### **What is the purpose of the study?**

People with chronic conditions have different experiences and find some difficulties alongside of their condition. There is surprisingly little research into living with epilepsy and I am interested in asking people who have epilepsy about their experiences. The results of this study will be useful for newly diagnosed people with epilepsy and for health care professionals who work with people with epilepsy.

You have been invited as you may suffer from epilepsy and I would like to chat with you about your experiences. If you are interested I will arrange a time to visit you, this should not take more than forty five minutes.

### **Do I have to take part?**

You do not have to take part, taking part is completely optional. However, if you want to participate, then you will be given this information sheet to keep and be asked to sign a consent form. You are completely free to stop participating whenever you like, without any reason. I will respect to your decision and your decision will not affect the standard of caring support you receive.

### **What will happen to me if I take part?**

If you decide to participate in this study, you need to contact me by emailing me at the address below or telephoning me at the number below. I will then arrange a time and place convenient to you to come and chat to you. I will ask you to sign a consent form and I will record our chat, but this is only to help me remember what you have said, no one else will hear the recording. I will ask you questions about what it is like for you, living with epilepsy.

**Will my taking part in this study be kept confidential?**

Our conversation will be confidential as no one else will hear the tape. I will transcribe the tape but no names will be used as your words will be allocated a number. The tape will be deleted after I have transcribed it. This research will hopefully be published and this may include quotes from our conversation, but no real names or identifying descriptions will be used in the write-up.

**What if there is a problem?**

If at any time you would like to speak to someone else about this study you may contact my supervisor, Dr Bridget Dibb [bridget.dibb@brunel.ac.uk](mailto:bridget.dibb@brunel.ac.uk), or Co-Chairs of the Brunel Psychology Research Ethics Committee, Professor Taeko Wydell at [taeko.wydell@brunel.ac.uk](mailto:taeko.wydell@brunel.ac.uk), or Dr Tara Marshal at [tara.marshall@brunel.ac.uk](mailto:tara.marshall@brunel.ac.uk).

**What are the other possible disadvantages and risks of taking part?**

The only disadvantage for you is that you will need to give some of your time to talk to me. In the unlikely event that you feel uncomfortable talking about your experience of epilepsy with me and you would prefer to stop, I will stop the recording, answer any questions you have, and stay with you until you feel comfortable again. We will not talk about your experiences again unless you feel happy about it. If you wish to stop participating in the study, you may do so without giving any reason.

Please note that this study is not linked to your health care and your participation will not affect your treatment.

If you would like to participate please contact me on the details below.

[Aisan.Ghaemianoskouei@brunel.ac.uk](mailto:Aisan.Ghaemianoskouei@brunel.ac.uk) or 07429350377

Please do not hesitate contact me for any enquiry you may have.

Thank you,  
Aisan

## Information sheet for Iranian participants

### برگه اطلاعات شرکت کننده

نام من آيسان است و دانشجوی دانشگاه دکتری رشته در بروئل هستم. اینجانب در صدد انجام تحقیقی در راستای بررسی تجربه زندگی با بیماری صرع می باشم.

من از افرادی که این بیماری را دارند دعوت می کنم تا در این تحقیق شرکت نمایند. افراد علاقمند می توانند با اینجانب، آيسان در مورد تجربه زندگی خود با بیماری صرع در زمان و مکانی که برایشان مناسب است، گفتگو نمایند. لازم است تا قبل از تصمیم گیری برای شرکت در این تحقیق، با ساختار آن آشنا شوید. لطفا اطلاعاتی را که در ادامه می آید، به دقت مطالعه نمایید.

#### هدف از این تحقیق چیست؟

افرادی که مبتلا به نوع مزمن این بیماری می باشند، تجربیات متفاوتی دارند. جای تعجب است که تحقیقات اندکی در رابطه با نحوه زندگی بیماران مبتلا به صرع انجام گرفته است و اینجانب علاقمند هستم تا در مورد تجربیات این افراد تحقیق نمایم. نتایج این تحقیق می تواند برای افرادی که این بیماری به تازگی در آنها تشخیص داده شده است و نیز متخصصان این امر، مفید واقع شود.

از آنجا که احتمالاً از بیماری صرع رنج می برید، از شما دعوت شده است تا در این تحقیق شرکت نمایید و من مایل هستم تا در مورد تجربیاتتان با شما گفتگویی داشته باشم. اگر مایل هستید، زمانی را برای ملاقات تعیین می نمایم که بیش از چهل و پنج به طول نمی انجامد.

#### آیا ملزم به شرکت در این تحقیق هستم؟

اجباری به شرکت در این تحقیق نبوده و این کار کاملاً داوطلبانه است. اما چنانچه خواهان شرکت کردن هستید، این برگه اطلاعات به شما داده خواهد شد و از شما خواسته می شود تا رضایت نامه ای را امضا نمایید. همچنین آزاد هستید تا هر زمان مایل بودید بدون نیاز به دلیل از ادامه کار سرباز زنید. تصمیم شما قابل احترام بوده و نحوه مراقبت از شما را تحت تاثیر قرار نخواهد داد.

#### شرکت در این تحقیق چگونه خواهد بود؟

چنانچه تصمیم به شرکت در این تحقیق گرفتید، می بایست از طریق آدرس ایمیل و یا شماره تلفنی که در پایین آمده است، با من تماس حاصل نمایید. سپس در زمان و مکان مورد نظر شما، با یکدیگر ملاقات کرده و صحبت می نمایم. ابتدا از شما می خواهم که فرم رضایت نامه را امضا نمایید و سپس به ضبط مکالماتمان می پردازم. این کارها برای به خاطر سپردن صحبت های شما است و فرد دیگری به آن دسترسی نخواهد داشت. سوالاتی که پرسیده می شود در رابطه با نحوه زندگی شما با بیماری صرع خواهد بود.

#### آیا شرکت من در این تحقیق محرمانه خواهد ماند؟

از آنجا که شخص دیگری مکالمات ما را نخواهد شنید، این مکالمات کاملاً محرمانه می ماند. نوار توسط من پیاده شده و نامی هیچ فردی آورده نخواهد شد. تنها شماره ای به کلمات شما اختصاص داده می شود. این نوار پس از پیاده سازی حذف می گردد. انتظار می رود این تحقیق به چاپ رسد و به مکالمات ما نیز در آن اشاره گردد، لیکن هیچ نام حقیقی و یا توضیحاتی که منجر به شناسایی گردد در آن استفاده نمی شود.

## اگر مشکلی بود چه باید کرد؟

چنانچه در هر زمان مایل به صحبت با فرد دیگری در رابطه با این تحقیق بودید، می توانید با استاد راهنمای اینجانب تماس حاصل نمایید.

### سایر مسائل و ریسک های احتمالی شرکت در این تحقیق

تنها مسئله موجود در این تحقیق، اختصاص کمی از وقت خود به صحبت با من است. در صورت احساس هرگونه ناراحتی نسبت به صحبت در مورد بیماری خود و تمایل به متوقف کردن گفتگو، ضبط صدا را متوقف کرده و به تمام سوالات احتمالی شما پاسخ می دهم و تا زمانی که دوباره احساس راحتی نمایید، صبر می نمایم. تنها در صورتی که صحبت در مورد بیماری و تجربیاتتان موجب احساس شادمانی در شما می شود، این کار انجام می گیرد. چنانچه به هر دلیلی مایل به ادامه این کار نبودید، می توانید آن را متوقف نمایید.

لطفاً در نظر داشته باشید که این تحقیق ارتباطی با سلامت و مراقبت های پزشکی شما نداشته و تاثیری بر روند درمانی تان نخواهد گذاشت.

در صورت تمایل به شرکت در این تحقیق، لطفاً با اطلاعاتی که در ذیل آمده با من تماس حاصل نمایید.

با تشکر

آیسان

**Appendix G: Consent form and Debriefing form for British and Iranian participants (Study 2)**

**INFORMED CONSENT SHEET**

**Coping with Epilepsy**

The Department of Psychology at Brunel University requires that all persons who participate in psychology studies give their written consent to do so. Please read the following and sign it if you agree with what it says.

I freely and voluntarily consent to be a participant in the research project entitled "Coping with epilepsy" to be conducted at Brunel University, with Aisan Ghaemian Oskouei as principal investigator. The broad goal of this research program is to explore (how people with epilepsy cope with their illness; and in particular if they pass urine, how do they manage their incontinency) specifically; I have been told that I will be asked to meet with Aisan and talk about living with epilepsy, what helps and what doesn't. The conversation should take no longer than one hour. I have been told that my responses will be kept strictly confidential. I also understand that if at any time during the session I feel unable or unwilling to continue, I am free to leave without negative consequences. That is, my participation in this study is completely voluntary, and I may withdraw from this study at any time. My withdrawal would not result in any penalty, academic or otherwise. My name will not be linked with the research materials, as the researchers are interested in investigating experience of people with epilepsy in general -- not any particular individual's idea in particular. I have been given the opportunity to ask questions regarding the procedure, and my questions have been answered to my satisfaction. I have been informed that if I have any general questions about this project, or ethical issues relating to the project, I should feel free to contact Aisan Ghaemian Oskouei at Aisan.Ghaemianoskouei@brunel.ac.uk. If I have any concerns or complaints regarding the way in which the research is or has been conducted I may contact one of the Co-Chairs of the Psychology Research Ethics Committee, Professor Taeko Wydell at [taeko.wydell@brunel.ac.uk](mailto:taeko.wydell@brunel.ac.uk) or Dr Tara Marshall at [tara.marshall@brunel.ac.uk](mailto:tara.marshall@brunel.ac.uk). I have read and understand the above and consent to participate in this study. My signature is not a waiver of any legal rights. Furthermore, I understand that I will be able to keep a copy of the informed consent form for my records.

Participant's Signature

Please Print

Date

I have explained and defined in detail the research procedure in which the above-named has consented to participate. Furthermore, I will retain one copy of the informed consent form for my records.

---

Principal Investigator Signature

Please Print

Date



**DEBRIEFING FORM for British participants (Study 2)**

**DEBRIEFING FORM**

Coping with epilepsy

In this study I'm interested in exploring how people cope with their epilepsy, what helps and what hinders in terms of coping with illness. In addition, I'm interested in exploring coping strategies with urinary pass, if they have any

The following studies might be of interest to you:

1. By [Fiona Marshall](#) & [Pamela Crawford](#) (2006). Coping with Epilepsy Book
2. <http://www.epilepsyresearch.org.uk/?s=coping&x=0&y=0> (Epilepsy Research UK)

**Thank you for taking part in this study**

## Consent form for Iranian participants (Study 2)

### برگه رضایت داوطلبانه

#### مقابله با صرع

افرادی که در تحقیقات روانشناسی دپارتمان روانشناسی دانشگاه بروئل شرکت می نمایند، ملزم به اعلام رضایت کتبی خود نسبت به این انجام کار می باشند. لطفاً متن زیر را مطالعه کرده و در صورت توافق آن را امضا نمایید.

اینجانب رضایت داوطلبانه خود را نسبت به شرکت در پروژه تحقیقاتی با عنوان " صرع با مقابله" که در دانشگاه بروئل و توسط آیسان قائمیان اسکویی به عنوان محقق اصلی برگزار می گردد، اعلام می دارم. هدف کلی از این برنامه تحقیقاتی بررسی (چگونگی کنار آمدن با این بیماری به ویژه با مشکل بی اختیاری ادرار، توسط مبتلایان به آن می باشد می باشد).

اینجانب آگاه هستم که از من خواسته خواهد شد تا با آیسان ملاقات کرده و در مورد تجربه زندگی با بیماری صرع و اینکه چه چیزهایی موجب سهولت آن شده و چیزهایی نه، صحبت نمایم. این مکالمه بیشتر از یک ساعت به طول نمی انجامد

اینجانب آگاه هستم که پاسخ هایم به طور حتم محرمانه خواهد ماند. همچنین آگاه هستم چنانچه هر زمان در طول جلسه، احساس نمایم دیگر قادر به ادامه کار نبوده و یا تمایلی به آن ندارم، می توانم جلسه را بدون هیچ پیامد منفی ترک نمایم. بر این اساس، شرکت من در تحقیق، کاملاً داوطلبانه بوده و هر زمان می توانم از شرکت در آن انصراف دهم. انصراف من منجر به هیچ گونه جریمه ای اعم از آکادمیک و یا غیره نخواهد شد. نام من با مواد تحقیق مرتبط نخواهد شد، چرا که محققان به دنبال تحقیق و بررسی در زمینه (کیفیت زندگی بیماران مبتلا به صرع) به طور کل بوده و نه بررسی نظرات فردی اشخاص. این فرصت به من داده شد تا سئولات خود را در رابطه با فرایند تحقیق مطرح نمایم و این سئولات به صورت قابل قبولی پاسخ داده شد. اینجانب آگاه هستم در صورت داشتن هرگونه سؤال در رابطه با پروژه و یا مسائل اخلاقی مربوط به آن، می توانم به راحتی آن را با آیسان در میان گذارم. همچنین در صورت وجود هرگونه نگرانی و یا شکایت در رابطه با نحوه اجرای تحقیق می توانم با یکی از مسئولان کمیته اخلاق در تحقیقات روانشناسی Professor Taeko Wydell at [taeko.wydell@brunel.ac.uk](mailto:taeko.wydell@brunel.ac.uk) or Dr Tara Marshall at [tara.marshall@brunel.ac.uk](mailto:tara.marshall@brunel.ac.uk). تماس برقرار نمایم.

اینجانب مطالب بالا را خوانده و متوجه شده و رضایت خود را نسبت به شرکت در این تحقیق اعلام می دارم. امضای اینجانب به معنای چشم پوشی از حقوق خود نمی باشد. به علاوه، آگاه هستم که می توانم یک کپی از این رضایت نامه را نزد خود نگاه دارم.

تاریخ

شرکت امضاء کننده

تاریخ

امضاء محقق

## DEBRIEFING FORM for Iranian participants (Study 2)

فرم گزارشگیری

در این مطالعه من علاقمند به جستجو استراتژی‌ها هستم و چگونگی کنار آمدن با این بیماری به ویژه با مشکل بی اختیاری ادرار، توسط مبتلایان به آن.

مطالعات زیر ممکن است مورد علاقه شما باشد:

از بیماری صرع بیشتر بدانید - مجله زندگی و سلامتی و سرگرمی

<http://magazine.a222.org/epilepsy/>

اطلاعات کتاب: زندگی با صرع "اثر زخمی در سر، نشانه‌ای از صرع"

بار دیگر، با تشکر از شما برای شرکت در این مطالعه

## Appendix H: Interview Schedule for British and Iranian participant (Study 1)

This interview consists of semi-structured interview covering questions in order to explore factors influence living with epilepsy.

Expected time: 45min- 1 hour

### **Demographic questions:**

Age, sex, ethnicity, type of epilepsy, time since diagnosis

### **Relevant questions about epilepsy**

- Can you explain to me what your feeling was when you first diagnosed with epilepsy?
- How long have you had epilepsy?
- Can you tell me about your experience of having a seizure? Can you expand on that? How do you find yourself?
- How often do you get seizure? Is there anything that can trigger your seizure?
- Do you take your medicine regularly?

### **Relevant questions to explore factors influencing with living with epilepsy**

- Can you tell me what it is like living with epilepsy? (Can you expanded on that, and how do you feel on that?)
- Do you think epilepsy changed your life since you have been diagnosed with it?
- Are there any other things that are important to you for living with epilepsy? (Can you give me one example of that?)
- How freely can you discuss your epilepsy with your friends?
- Can you tell me what bothers you in living with epilepsy?
- How do you evaluate yourself in interacting socially?
- Do you have anything to add?

## Interview Schedule for Iranian participants (Study 1)

بر نامه مصاحبه (مطالعه اول)

مصاحبه حاضر شامل سوالاتی نیمه ساختار یافته جهت بررسی عوامل موثر بر زندگی با بیماری صرع می باشد.

مدت زمان لازم: 45 دقیقه تا 1 ساعت

سوالات دموگرافیک (جمعیت شناختی)

سن، جنسیت، نوع صرع، قومیت، مدت زمان سپری شده از تشخیص بیماری

### سوالات مربوط به بیماری صرع

- می توانید احساس خود را زمانی که بیماری صرع برای اولین بار در شما تشخیص داده شد، بیان کنید؟
- می توانید در ارتباط با تجربه تان از حمله این بیماری صحبت کنید؟ می توانید آن را شرح دهید؟ در آن لحظه چه حالتی دارید؟
- بعد از حمله چه احساسی دارید؟
- هر چند وقت یکبار این حمله به شما دست می دهد؟ آیا چیزی هست که باعث این حمله در شما گردد؟ آیا داروهای خود را مرتب مصرف می کنید؟

### سوالات مربوط به عوامل موثر بر زندگی با بیماری صرع:

- می توانید توضیح دهید که زندگی با بیماری صرع چگونه می تواند باشد؟ (می توانید آن را شرح دهید و از احساس خود در این مورد بگویید؟)
- آیا فکر می کنید این بیماری از زمانی که در شما تشخیص داده شد، زندگی تان را تغییر داده است؟
- آیا موضوعی هست که در زندگی با بیماری صرع، برایتان مهم باشد؟ (آیا می توانید یک مورد را بیان کنید؟)
- هر چند وقت یکبار به راحتی در مورد بیماری تان با دوستان خود صحبت می کنید؟
- می توانید بگویید چه چیز در زندگی با بیماری صرع شما را آزار می دهد؟
- تعاملات اجتماعی خود را چگونه ارزیابی می کنید؟
- آیا موردی برای اضافه کردن دارید؟

## Appendix- I Interview Schedule for British and Iranian participants (Study 2)

This interview consists of semi-structured interview covering questions in order to explore coping strategies in living with epilepsy.

Expected time: 45min- 1 hour

### **Demographic questions:**

Age, sex, ethnicity, type of epilepsy, time since diagnosis

- Can you tell me how do you cope with your epilepsy? can you give me an example
- What do you think is helpful when you are coping with your illness?
- Are you passing urine during the seizure? If so how do you cope with it?
- What helps you in coping with your incontinency?

## Interview Schedule for Iranian participant (Study 2)

بر نامه مصاحبه (مطالعه دوم)

مصاحبه حاضر شامل سوالاتی نیمه ساختار یافته جهت بررسی استراتژی های موثر بر زندگی با بیماری صرع و بررسی نحوه کنار آمدن شما با بیماری تان می باشد.

مدت زمان لازم: 45 دقیقه تا 1 ساعت

سوالات دموگرافیک (جمعیت شناختی)

سن، جنسیت، نوع صرع، قومیت، مدت زمان سپری شده از تشخیص بیماری

- می توانید بگویید که چگونه با بیماری خود کنار می آید؟
- فکر می کنید چه چیز در کنار آمدن با بیماری تان موثر است؟
- آیا در حین حمله دچار دفع ادرار می شوید؟
- چه چیز در اداره مشکل بی اختیاری ادرار، به شما کمک می نماید؟

## **Appendix J: Confirmation letter from Epilepsy Research UK (Study 3)**

"Dear Aisan

Thank you for getting back to me. I can confirm that Epilepsy Research UK is happy to publish your survey in its June 2014 e-newsletter.

All the best,

**Delphine van der Pauw**

Email: [Delphine@eruk.org.uk](mailto:Delphine@eruk.org.uk)

Website: [www.epilepsyresearch.org.uk/](http://www.epilepsyresearch.org.uk/)"



## Appendix K: Consent form for British and Iranian participants (Study 3)

### Predictors of quality of life in people with epilepsy

The Department of Psychology at Brunel University requires that all persons who participate in psychology studies give their written consent to do so. Please read the following and sign it if you agree with what it says. I freely and voluntarily consent to be a participant in the research project entitled "Predictors of quality of life in people with epilepsy" to be conducted at Brunel University, with (Aisan Ghaemian Oskouei) principal investigator. The broad goal of this research program is to explore factors that predict quality of life in people living with epilepsy. Specifically, I have been told that I will be asked to complete questionnaires. The session should take no longer than 20 minutes to complete.

I have been told that my responses will be kept strictly confidential. I also understand that if at any time during the session I feel unable or unwilling to continue, I am free to leave without negative consequences. That is, my participation in this study is completely voluntary, and I may withdraw from this study at any time. My withdrawal would not result in any penalty, academic or otherwise. My name will not be linked with the research materials, as the researchers are interested in exploring factors which will predict a quality of life in living with epilepsy in general -- not any particular individual's experience in particular. I have been given the opportunity to ask questions regarding the procedure, and my questions have been answered to my satisfaction. I have been informed that if I have any general questions about this project, or ethical issues relating to the project, I should feel free to contact Aisan Ghaemian Oskouei at [aisan.ghaemianoskouei@brunel.ac.uk](mailto:aisan.ghaemianoskouei@brunel.ac.uk). If I have any concerns or complaints regarding the way in which the research is or has been conducted I may contact the Chair of the Psychology Research Ethics Committee Dr Achim Schuetzwohl at [achim.schuetzwohl@brunel.ac.uk](mailto:achim.schuetzwohl@brunel.ac.uk).

I have read and understand the above and consent to participate in this study. My signature is not a waiver of any legal rights. Furthermore, I understand that I will be able to keep a copy of the informed consent form for my records.

### Consent form for Iranian participants (Study 3)

#### برگه رضایت داوطلبانه

#### عوامل موثر در زندگی با صرع

افرادی که در تحقیقات روانشناسی دپارتمان روانشناسی دانشگاه بروئل شرکت می نمایند، ملزم به اعلام رضایت کتبی خود نسبت به این انجام کار می باشند. لطفاً متن زیر را مطالعه کرده و در صورت توافق آن را امضا نمایید.

اینجانب رضایت داوطلبانه خود را نسبت به شرکت در پروژه تحقیقاتی با عنوان " صرع زندگی در موثر عوامل " که در دانشگاه بروئل و توسط آیسان قائمیان اسکویی به عنوان محقق اصلی برگزار می گردد، اعلام می دارم.

اینجانب آگاه هستم که از من خواسته خواهد شد. بکنم پر را نظر مورد های پرسشنامه اینجانب آگاه هستم که پاسخ هایم به طور حتم محرمانه خواهد ماند. همچنین آگاه هستم چنانچه هر زمان ، احساس نمایم دیگر قادر به ادامه کار نبوده و یا تمایلی به آن ندارم، می توانم ترک نمایم. بر این اساس، شرکت من در تحقیق، کاملاً داوطلبانه بوده و هر زمان می توانم از شرکت در آن انصراف دهم. انصراف من منجر به هیچ گونه جریمه ای اعم از آکادمیک و یا غیره نخواهد شد. نام من با مواد تحقیق مرتبط نخواهد شد، چرا که محققان به دنبال تحقیق و بررسی در زمینه (کیفیت زندگی بیماران مبتلا به صرع) به طور کل بوده و نه بررسی نظرات فردی اشخاص. این فرصت به من داده شد تا سئولات خود را در رابطه با فرایند تحقیق مطرح نمایم و این سئولات به صورت قابل قبولی پاسخ داده شد. اینجانب آگاه هستم در صورت داشتن هرگونه سؤال در رابطه با پروژه و یا مسائل اخلاقی مربوط به آن، می توانم به راحتی آن را با آیسان در میان گذارم. همچنین در صورت وجود هرگونه نگرانی و یا شکایت در رابطه با نحوه اجرای تحقیق می توانم با یکی از مسئولان کمیته اخلاق در تحقیقات روانشناسی تماس برقرار نمایم. Professor Taeko Wydell at [taeko.wydell@brunel.ac.uk](mailto:taeko.wydell@brunel.ac.uk) or Dr Tara Marshall at [tara.marshall@brunel.ac.uk](mailto:tara.marshall@brunel.ac.uk).

اینجانب مطالب بالا را خوانده و متوجه شده و رضایت خود را نسبت به شرکت در این تحقیق اعلام می دارم. امضای اینجانب به معنای چشم پوشی از حقوق خود نمی باشد. به علاوه، آگاه هستم که می توانم یک کپی از این رضایت نامه را نزد خود نگاه دارم.

تاریخ

شرکت امضاء کننده

تاریخ

امضاء محقق



These questions are about how you **FEEL** and how things have been for you during the **past 4 weeks**. For each question, please indicate the one answer that comes closest to the way you have been feeling.

How much of the time during the **past 4 weeks**...

*(Circle one number on each line)*

	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
2. Did you feel full of pep?	1	2	3	4	5	6
3. Have you been a very nervous person?	1	2	3	4	5	6
4. Have you felt so down in the dumps that nothing could cheer you up?	1	2	3	4	5	6
5. Have you felt calm and peaceful?	1	2	3	4	5	6
6. Did you have a lot of energy?	1	2	3	4	5	6
7. Have you felt downhearted and blue?	1	2	3	4	5	6
8. Did you feel worn out?	1	2	3	4	5	6
9. Have you been a happy person?	1	2	3	4	5	6
10. Did you feel tired?	1	2	3	4	5	6
11. Have you worried about having another seizure?	1	2	3	4	5	6
12. Did you have difficulty reasoning and solving problems (such as making plans, making decisions, learning new things)?	1	2	3	4	5	6
13. Has your health limited your social activities (such as visiting with friends or close relatives)?	1	2	3	4	5	6

14. How has the **QUALITY OF YOUR LIFE** been during the **past 4 weeks** (that is, how have things been going for you)?

*(Circle one number)*

	Very well: could hardly be better	1
	Pretty good	2
	Good & bad parts about equal	3
	Pretty bad	4
	Very bad: could hardly be worse	5

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The following question is about **MEMORY**.

(Circle one number)

	Yes, a great deal	Yes, somewhat	Only a little	No, not at all
15. In the past 4 weeks, have you had any trouble with your memory?	1	2	3	4

Circle one number for **how often** in the **past 4 weeks** you have had trouble *remembering* or **how often** this memory problem has interfered with your normal work or living.

	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
16. Trouble remembering things people tell you	1	2	3	4	5	6

The following questions are about **CONCENTRATION** problems you may have. Circle one number for **how often** in the **past 4 weeks** you had trouble concentrating or **how often** these problems interfered with your normal work or living.

	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
17. Trouble concentrating on reading	1	2	3	4	5	6
18. Trouble concentrating on doing one thing at a time	1	2	3	4	5	6

The following questions are about problems you may have with certain **ACTIVITIES**. Circle one number for **how much** during the **past 4 weeks** your epilepsy or antiepileptic medication has caused trouble with...

	A great deal	A lot	Somewh at	Only a little	Not at all
19. Leisure time (such as hobbies, going out)	1	2	3	4	5
20. Driving	1	2	3	4	5

The following questions relate to the way you **FEEL** about your **seizures**.

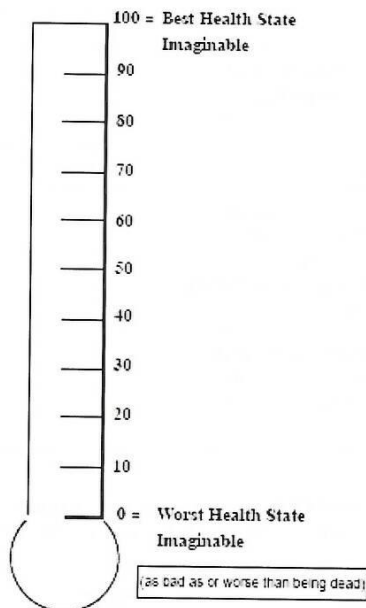
(Circle one number on each line)

		Very fearful	Somewhat fearful	Not very fearful	Not fearful at all
21.	How fearful are you of having a seizure during the next month?	1	2	3	4
		Worry a lot	Occasionally worry	Don't worry at all	
22.	Do you worry about hurting yourself during a seizure?	1	2	3	
		Very worried	Somewhat worried	Not very worried	Not at all worried
23.	How worried are you about embarrassment or other social problems resulting from having a seizure during the next month?	1	2	3	4
24.	How worried are you that medications you are taking will be bad for you if taken for a long time?	1	2	3	4

For each of these **PROBLEMS**, circle one number for **how much they bother you** on a scale of 1 to 5 where 1 = Not at all bothersome, and 5 = Extremely bothersome.

		Not at all bothersome			Extremely bothersome	
		1	2	3	4	5
25.	Seizures	1	2	3	4	5
26.	Memory difficulties	1	2	3	4	5
27.	Work limitations	1	2	3	4	5
28.	Social limitations	1	2	3	4	5
29.	Physical effects of antiepileptic medication	1	2	3	4	5
30.	Mental effects of antiepileptic medication	1	2	3	4	5

31. How good or bad do you think your health is? On the thermometer scale below, the best imaginable state of health is 100 and the worst imaginable state is 0. Please indicate how you feel about your health by circling one number on the scale. Please consider your epilepsy as part of your health when you answer this question.







# Hospital Anxiety and Depression Scale



Name ..... Date .....

Clinicians are aware that emotions play an important part in most illnesses. If your clinician knows about these feelings she or he will be able to help you more.

This questionnaire is designed to help your clinician to know how you feel. Ignore the numbers printed on the left of the questionnaire. Read each item and **underline** the reply which comes closest to how you have been feeling in the past week.

Don't take too long over your replies; your immediate reaction to each item will probably be more accurate than a long thought-out response.

fold along dashed line

A	
3	
2	
1	
0	
D	
0	
1	
2	
3	
A	
3	
2	
1	
0	

**I feel tense or 'wound up':**

Most of the time

A lot of the time

From time to time, occasionally

Not at all

**I still enjoy the things I used to enjoy:**

Definitely as much

Not quite so much

Only a little

Hardly at all

**I get a sort of frightened feeling as if something awful is about to happen:**

Very definitely and quite badly

Yes, but not too badly

A little, but it doesn't worry me

Not at all

*(continued overleaf)*



# ROSENBERG SELF-ESTEEM SCALE



Name: .....

Date: ..... Record Number: .....

Here is a list of statements dealing with your general feelings about yourself. If you **agree** with the statement, circle A. If you **strongly agree**, circle SA. If you **disagree**, circle D. If you **strongly disagree**, circle SD. Thank you.

	1	2	3	4
	Strongly agree	Agree	Disagree	Strongly disagree
1. On the whole, I am satisfied with myself.	SA	A	D	SD
2. At times I think I am no good at all.	SA	A	D	SD
3. I feel that I have a number of good qualities.	SA	A	D	SD
4. I am able to do things as well as most other people.	SA	A	D	SD
5. I feel I do not have much to be proud of.	SA	A	D	SD
6. I certainly feel useless at times.	SA	A	D	SD
7. I feel that I'm a person of worth, at least on an equal plane with others.	SA	A	D	SD
8. I wish I could have more respect for myself.	SA	A	D	SD
9. All in all, I am inclined to feel that I am a failure.	SA	A	D	SD
10. I take a positive attitude toward myself.	SA	A	D	SD

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## -The Seizure Severity Questionnaire

<b>SEIZURE SEVERITY QUESTIONNAIRE:</b>	<b>SSQ</b> <small>(Version 3)</small>
Seizure Severity Questionnaire (SSQ) ©, Version 3, copyright J. A. Cramer, 2003. All rights reserved.	

Today's Date: \_\_\_\_\_ / \_\_\_\_\_ / \_\_\_\_\_  
mm                      dd                      yy

Name: \_\_\_\_\_

The Seizure Severity Questionnaire (SSQ) is a review of various aspects of seizures. The person who has seizures may ask people who have observed the seizures (family, friends) to help answer some of the questions asking about events, but not about feelings. Only the person who has seizures knows how it feels.

There are 11 questions in three sections asking about events before, during, and after typical seizures. Please describe the **MOST COMMON TYPE OF SEIZURE** when answering the questions. If you are unsure about how to answer a question, please give the best answer you can and write a comment or explanation on the side of the page. These notes may be useful if you discuss the SSQ with your doctor. Completing the SSQ before and after treatment changes may help you and your doctor understand how the changes have affected your life.

*This copy of the SSQ is provided by [www.epilepsy.com](http://www.epilepsy.com), your source for epilepsy information.  
We wish you success in living your life with epilepsy!*

When answering the following questions, please mark or circle the number that best describes your feelings about each topic for your most common type of seizure. For example, "Somewhat helpful"  4

**BEFORE SEIZURES** most common type

**1. Did you have a warning (aura) BEFORE this type of seizure (smell, feeling, sensation, etc.) in the past 4 weeks?**  
 Yes  No [If no, skip to question 2]

**1A. If "yes", was the warning (aura) HELPFUL; for example, did it allow you to prepare for the seizure?**

1      2      3       4      5      6      7  
very helpful                      somewhat helpful                      no help

**DURING SEIZURES** most common type

**2. Did you have movements or actions DURING this type of seizure in the past 4 weeks (such as automatic movements, uncontrollable actions, falling, injury, tongue biting, wetting pants with urine, etc.)?**  
 Yes  No [If no, skip to question 3]

**2A. If yes, how SEVERE (INTENSE) were the movements or actions overall?**

1      2      3       4      5      6      7  
very mild                      moderate                      very severe

**2B. How BOTHERSOME (interfere with your life) were the movements or actions overall?**

1      2      3       4      5      6      7  
no bother at all                      moderate                      very bothersome

When answering the following questions, please mark or circle the number that best describes your feelings about each topic for your most common type of seizure. For example, "Sometimes" 4

3. Did you have ONLY altered consciousness (blank-out) or sensations (no movements or actions) with this type of seizure in the past 4 weeks?  
 Yes  No [If no, skip to question 4]

3A. If yes, how BOTHERSOME (interfere with your life) were these periods of altered consciousness?

1 2 3 4 5 6 7  
no bother at all moderate very bothersome

**AFTER SEIZURES** most common type

4. Did it take a while to recover (get back to normal) AFTER this type of seizure in the past 4 weeks  
 Yes  No, I recovered immediately from my seizures. [If no, skip to question 8]

5. Did you have Cognitive Effects (confusion, loss of memory or speech, walk or talk without purpose, etc.) AFTER seizures?  
 Yes  No [If no, skip to question 6]

5A. If yes, how OFTEN did you have Cognitive Effects AFTER seizures?

1 2 3 4 5 6 7  
never sometimes always

5B. How SEVERE (INTENSE) were the Cognitive Effects AFTER seizures?

1 2 3 4 5 6 7  
very mild moderate very severe

5C. How BOTHERSOME were the Cognitive Effects AFTER seizures?

1 2 3 4 5 6 7  
no bother at all moderate very bothersome

6. Did you have Emotional Effects (depression, anxiety, anger, etc.) AFTER seizures?  
 Yes  No [If no, skip to question 7]

6A. If yes, how OFTEN did you have Emotional Effects AFTER seizures?

1 2 3 4 5 6 7  
never sometimes always

6B. How SEVERE (INTENSE) were the Emotional Effects AFTER seizures?

1 2 3 4 5 6 7  
very mild moderate very severe

6C. How BOTHERSOME were the Emotional Effects AFTER seizures?

1 2 3 4 5 6 7  
no bother at all moderate very bothersome

When answering the following questions, please mark or circle the number that best describes your feelings about each topic for your most common type of seizure. For example, "Moderate" 4

7. Did you have Physical Effects (sleepy, tired, weak, sore muscles, headache) AFTER seizures?

Yes  No [If no, skip to question 8]

7A. If yes, how OFTEN did you have Physical Effects AFTER seizures?

1 2 3 4 5 6 7  
never sometimes always

7B. How SEVERE (INTENSE) were the Physical Effects AFTER seizures?

1 2 3 4 5 6 7  
very mild moderate very severe

7C. How BOTHERSOME were the Physical Effects AFTER seizures?

1 2 3 4 5 6 7  
no bother at all moderate very bothersome

### OVERALL ASSESSMENT

Include your feeling about all types of seizures you have had recently.

8. How SEVERE (INTENSE) were your seizures overall in the past 4 weeks?

1 2 3 4 5 6 7  
very mild moderate very severe

9. How BOTHERSOME (interfere with your life) were your seizures overall in the past 4 weeks?

1 2 3 4 5 6 7  
no bother at all moderate very bothersome

10. What is most bothersome about your seizures overall (mark only one):

- Warning (aura) before the seizure
- Activities during the seizure
- Recovery after the seizure

Answer question 11 only after a change in seizure treatment:

11. How have your seizures changed in severity or bothersomeness since changing seizure treatment? (circle one number)

much worse				no change				much better						
-7	-6	-5	-4	-3	-2	-1	0	+1	+2	+3	+4	+5	+6	+7

This copy of the SSQ is provided by [www.epilepsy.com](http://www.epilepsy.com), your source for epilepsy information.  
We wish you success in living your life with epilepsy!

## -The Social Comparison Scale

### Identification/Contrast scale (Van der Zee, Buunk, Sanderman, Botke, & Van den Bergh, 2000)

There are 12 statements regarding comparison with other people. I would like to find out how you compare yourself with others. In this case I would like to indicate how much you agree with each statement below.

- | A          | B | C | D | E              |
|------------|---|---|---|----------------|
| Not at all |   |   |   | Strongly agree |
| 1.         |   |   |   |                |
| 2.         |   |   |   |                |
| 3.         |   |   |   |                |
| 4.         |   |   |   |                |
| 5.         |   |   |   |                |
| 6.         |   |   |   |                |
| 7.         |   |   |   |                |
| 8.         |   |   |   |                |
| 9.         |   |   |   |                |
| 10.        |   |   |   |                |
| 11.        |   |   |   |                |
| 12.        |   |   |   |                |
1. When I see others who are doing worse, I experience fear that my health status will decline.
  2. When I see others who are doing worse, I experience fear that my future will be similar.
  3. When I see others who are doing worse, I experience fear that I will go along the same way.
  4. When I see others who experience more difficulties than I do, I am happy that I am doing so well myself.
  5. When I see others who experience more difficulties than I do, I feel relieved about my own situation.
  6. When I see others who experience more difficulties than I do, I realize how well I am doing.
  7. When I meet others who are experiencing less problems than I am, it makes me happy realizing that it is possible for me to improve.
  8. When I meet others who are experiencing less problems than I am, I am pleased that things can get better.
  9. When I meet others who are experiencing less problems than I am, I have good hope that my situation will improve.
  10. When I think about others who are doing better than I am, it is threatening to notice that I am doing not so well.
  11. When I think about others who are doing better than I am, I feel frustrated about my own situation.
  12. When I think about others who are doing better than I am, I feel depressed realizing that I am not so well off.

## Appendix M: Persian version of the Questionnaires

### -The quality of life Questionnaire

کیفیت زندگی بیماری صرع - QOLIE - ویرایش اول

تاریخ ..... / ..... / .....

نام بیمار .....

سن بیمار: .....

---

#### دستورالعمل

QOLIE یک مقیاس ارزیابی کیفیت زندگی بزرگسالان ( افراد بالاتر از 18 سال) در بیماران مبتلا به صرع است. [ نوجوانان ( افراد 11- 17 سال) بهتر است مقیاس ارزشیابی QOLIE\_AD\_48 را، که مناسب این گروه سنی طراحی شده است، تکمیل کنند.] بهتر است این پرسشنامه لزوماً توسط شخص مبتلا به بیماری صرع ( و نه توسط همراه یا دوست بیمار) تکمیل شود، زیرا سایرین لزوماً از احساسات شما مطلع نمی باشند.

در این پرسشنامه تعداد 31 سوال در مورد سلامتی و فعالیتهای روزمره شما وجود دارد. به هریک از سوالات با در داخل کادر قرار دادن عدد مناسب آن ( 1، 2، 3 و ...) پاسخ دهید. در صورت عدم اطمینان از چگونگی پاسخ به یک سوال، می توانید مناسبترین عدد را انتخاب کرده و سپس توضیحی را در کنار سوال پادداشت کنید. این پادداشتهای می توانند در صورت گفتگوی شما با پزشک معالجتان در مورد QOLIE\_31 مورد استفاده قرار گیرند. تکمیل پرسشنامه QOLIE\_31 در مراحل قبل و بعد از روند تغییرات درمانی، احتمالاً در تشخیص چگونگی تاثیر تغییرات زندگیانتان، به شما و پزشک معالجتان کمک شایانی نماید.

---

1. به طور کلی ارزیابی شما از کیفیت زندگیانتان چیست؟

(یکی از اعداد مقیاس زیر را در داخل کادر قرار دهید.)





بهرترین  
کیفیت  
زندگی

پایین ترین  
کیفیت زندگی

سوالات زیر به چگونگی احساسات شما و اینکه به چه نحوی مسائل در طی 4 هفته اخیر برای شما رقم خورده است، مربوط اند.

چه مقدار از اوقات 4 هفته اخیر .....

(در هریک از خطوط عدد دلخواه را در داخل کادر قرار دهید)

همیشه	غالبا	معمولا	بعضا	به هرگز	ندرت	
1	2	3	4	5	6	1. احساس پشیمانی داشته اید؟
1	2	3	4	5	6	2. یک فرد عصبی بوده اید؟
1	2	3	4	5	6	3. بصورتی ناراحت و دماغ بوده اید بطوریکه هیچ چیز نمی تواند شادتان کند؟
1	2	3	4	5	6	4. احساس آرامش و خونسردی داشته اید؟
1	2	3	4	5	6	5. انرژی زیادی داشته اید؟
1	2	3	4	5	6	6. احساس دلشکستگی و ماتم داشته اید؟
1	2	3	4	5	6	7. احساس فرسودگی داشته اید؟
1	2	3	4	5	6	8. فرد شادی بوده اید؟
1	2	3	4	5	6	9. احساس خستگی کرده اید؟
1	2	3	4	5	6	10. نگران بروز یک حمله ناگهانی دیگر بوده اید؟

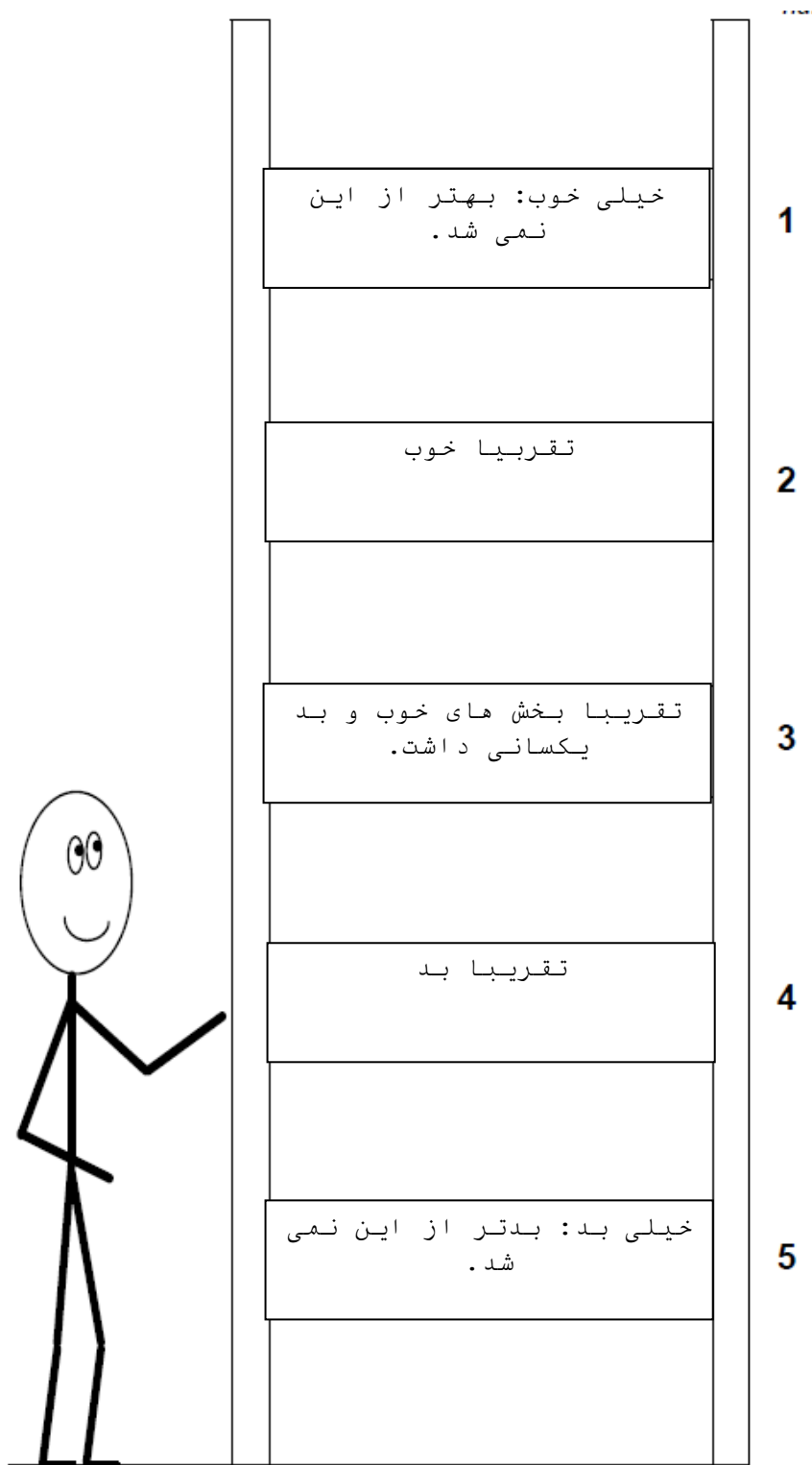
بهرترین  
کیفیت  
زندگی



6	5	4	3	2	1	11. در حل و دلیل یابی مسائل مختلف (همچون برنامه ریزی، تصمیم گیری و یادگیری مسائل جدید) مشکل داشته اید؟
6	5	4	3	2	1	12. آیا وضع سلامتیتان فعالیت‌های اجتماعی شما (همچون دیدار با دوستان و بستگان) را محدود کرده است؟

2. 14. کیفیت زندگی شما در طول 4 هفته اخیر چگونه بوده است؟ (به عبارت دیگر، چه میزان در این مدت مسائل بر وفق مرادتان بوده است.)

(عدد دلخواه را داخل کادر قرار دهید .)



سوال بعدی در مورد وضعیت حافظه شما می باشد

بلی، همیشه	بلی، نسبتاً	بصورت محدود	نه، اصلاً
1	2	3	4

15. طی چهار هفته اخیر آیا با وضعیت حافظه تان مشکلی داشته اید؟

به چه میزان در طی چهار هفته اخیر در یادآوری مسائل مشکل داشته اید و یا به چه میزان مشکلات حافظه ای روند عادی کار یا زندگی تان را دچار اختلال کرده است؟

همیشه	اکثر اوقات	معمولاً	بعضاً	به ندرت	هیچگاه
1	2	3	4	5	6

16. مشکل یادآوری گفته های دیگران به شما

سوالات بعدی در مورد مشکلات تمرکز شماست. به چه میزان در طی چهار هفته اخیر در تمرکز کردن مشکل داشته اید و یا به چه میزان این مشکلات روند عادی کار یا زندگی تان را دچار اختلال کرده است؟

همیشه	اکثر اوقات	معمولاً	بعضاً	به ندرت	هیچگاه
1	2	3	4	5	6

17. مشکل در تمرکز حواستان در خواندن

18. مشکل در تمرکز در انجام یک کار بخصوص در یک زمان معین

سوالات بعدی در مورد مشکلات احتمالی شما در انجام فعالیت های مشخص اند. به چه میزان در طی چهار هفته اخیر بیماری صرع یا روند درمانی آن باعث بروز مشکل در ..... شده است؟

همیشه	اکثر اوقات	بعضاً	به ندرت	هیچگاه
1	2	3	4	5

19. فعالیتهای مربوط به اوقات فراغت

20. رانندگی اتومبیل

سوالات بعدی به چگونگی احساسات شما درباره حملات ناگهانی بیماربتان مرتبط است.

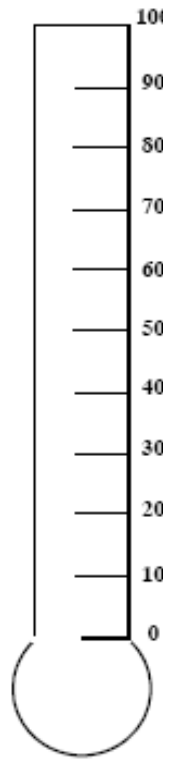
(عدد دلخواه را در داخل کادر قرار دهید.)

بسیار زیاد	نسبتا	بسیار کم	اصلا
1	2	3	4
21. تا چه حد نگران بروز ناگهانی حملات بیماری در یک ماه آتی هستید؟			
شدیدا نگران	نگرانی نسبی	اصلا نگران نیستم	
1	2	3	
22. آیا در مورد آسیب زدن به خود طی حملات ناشی از بیماری نگرانی دارید؟			
بسیار زیاد	نسبتا	بسیار کم	اصلا
1	2	3	4
23. در طی یک ماه آتی، به چه میزان نگران ایجاد خجالت زدگی و سایر مشکلات اجتماعی در نتیجه بروز حمله ناگهانی بیماری در جمع هستید؟			
1	2	3	4
24. در صورت طولانی بودن روند درمان دارویی بیمارتان، به چه میزان نگران ناکارآمدی این روند هستید؟			

برای هریک از مشکلات ذکر شده در سوالات بعدی، یکی از اعداد را، که نشان دهنده میزان آزاردهندگی آن مورد می باشد، به دلخواه داخل کادر قرار دهید.

اصلا آزاردهنده نیست	بسیار آزاردهنده است		
1	2	3	4
5			
25. حملات ناگهانی بیماری			
1	2	3	4
5			
26. مشکلات حافظه			
1	2	3	4
5			
27. محدودیتهای شغلی			
1	2	3	4
5			
28. محدودیتهای اجتماعی			
1	2	3	4
5			
29. اثرات جانبی فیزیکی (بدنی) روند درمان			
1	2	3	4
5			
30. اثرات جانبی ذهنی روند درمان			

31. به نظرتان، وضعیت سلامتی شما در چه حدی است؟ در 3 مقیاس درجه بندی زیر، مطلوبترین وضعیت سلامتی قابل تصور 100 و نامطلوبترین وضعیت نیز 0 در نظر گرفته شده است. **لطفا با احتساب بیماری صرع به عنوان بخشی از وضعیت جسمانی خود، عدد دلخواه را داخل کادر قرار دهید.**



## -The Hospital-Anxiety Questionnaire

### مقیاس اضطراب و افسردگی هاسپیتال کاتر و همکاران (2006)

نام و نام خانوادگی: تاریخ: سن:

این بخش به بررسی چگونگی احساس شما اختصاص دارد. هر ماده را بخوانید و آنگاه با توجه به احساسی که در چند هفته گذشته داشتید در مربع روبروی هر گزینه علامت تیک ✓ بزنید. برای پاسخ دادن وقت زیادی تلفن نکنید. واکنش فوری شما نسبت به هر ماده، احتمالاً دقیق‌تر از پاسخی خواهد بود که با فکر زیاد همراه است.

در هر سؤال فقط یک گزینه را علامت بزنید.

ردیف	عبارت	رتبه	✓
۱	احساس تنیدگی یا از هم گسیختگی می‌کنم.	اغلب اوقات	
		مدت زمان زیادی	
		گاهی اوقات	
		هیچوقت	
۲	احساس می‌کنم که انگار کم تحرک شده‌ام.	تقریباً همیشه	
		اغلب اوقات	
		گاهی اوقات	
		هیچوقت	
۳	هنوز از چیزهایی که قبلاً لذت می‌بردم «احساس لذت می‌کنم».	دقیقاً به همان اندازه	
		نه کاملاً به همان قدر	
		فقط اندکی	
		به هیچ وجه	
۴	نوعی احساس ترس وجودم را فرا گرفته: دلم مثل سیر و سرکه می‌جوشد.	به هیچ وجه	
		گاهی اوقات	
		اغلب اوقات	
		تقریباً همیشه	
۵	نوعی احساس ترس دارم، مثل اینکه اتفاق بدی در حال وقوع است.	البته، و کاملاً هم بد	
		بله، اما نه چندان بد	
		کمی، اما مرا نگران نمی‌کند	
		به هیچ وجه	
۶	دیگر به ظاهر نمی‌رسم.	کاملاً	
		آنقدر که باید به خودم نمی‌رسم.	
		ممکن است کاملاً مثل گذشته به خودم نرسم.	
		مثل همیشه به خودم می‌رسم	

ردیف	عبارت	رتبه	✓
۷	من می‌توانم بخندم و نکات خنده‌آور را تشخیص دهم.	به همان اندازه که قبلاً می‌توانستم	
		نه کاملاً به اندازه گذشته	
		مسلماً نه به اندازه گذشته	
		به هیچ وجه	
۸	آرام و قرار ندارم، گویی مجبورم پیوسته در حرکت باشم.	در واقع خیلی زیاد	
		زیاد	
		نه خیلی زیاد	
		به هیچ وجه	
۹	افکار نگران‌کننده‌ای به ذهنم خطور می‌کند.	در اکثر مواقع	
		بسیاری اوقات	
		گاهی اوقات، اما نه خیلی زیاد	
		فقط برخی مواقع	
۱۰	در انتظار چیزهای خوشایندم.	درست مثل گذشته	
		اندکی کمتر از گذشته	
		کاملاً کمتر از گذشته	
		به هیچ وجه	
۱۱	احساس نشاط می‌کنم.	به هیچ وجه	
		اندکی	
		گاهی اوقات	
		بیشتر مواقع	
۱۲	ناگهان احساس وحشت‌زدگی می‌کنم.	براستی اغلب اوقات	
		تقریباً اغلب موارد	
		نه خیلی زیاد	
		به هیچ وجه	
۱۳	می‌توانم به راحتی بنشینم و در جای خود آرام بگیرم.	کاملاً	
		معمولاً	
		اندکی	
		به هیچ وجه	
۱۴	می‌توانم از یک کتاب خوب یا برنامه رادیویی یا تلویزیونی لذت ببرم.	غالباً	
		گاهی اوقات	
		اندکی	
		خیلی به ندرت	

## -The Self-Esteem questionnaire

هر یک از عبارات های زیر را بخوانید. به هر عبارت با توجه به میزان توصیف آن درباره خودتان پاسخ دهید.

کاملاً مخالف	مخالف	موافق	کاملاً موافق	عبارات ها
				1- احساس می کنم انسان با ارزشی هستم.
				2- احساس می کنم چند ویژگی خوب دارم.
				3- می توانم به خوبی اکثر مردم کارها را انجام دهم.
				4- نسبت به خودم نگرش مثبت دارم.
				5- به طور کلی، از خودم راضی هستم.
				6- احساس می کنم چیز زیادی ندارم که به آن ها افتخار کنم.
				7- با در نظر گرفتن همه چیزها ، معمولاً فکر می کنم شکست خورده ام.
				8- ای کاش می توانستم احترام بیشتری به خودم قائل می شدم.
				9- گاهی احساس می کنم بی فایده هستم.
				10- گاهی فکر می کنم اصلاً نمی توانم کاری انجام دهم.



## -The Social Comparison Scale

شناسایی/مقیاس تغایر (ون در زی، بانک، ساندرمن، بوتک، ون دن برگ، 2000)

12 عبارت در رابطه با مقایسه خود با سایر افراد در ذیل آمده است. می خواهم بدانم که شما چگونه خود را با دیگران مقایسه می کنید و چه میزان با هر کدام از این عبارات موافق هستید.

- | الف | ب  | ج | د             |
|-----|--|---|---------------|
|     | به هیچ وجه   |   | کاملاً موافقم |
| 1.  | با دیدن افرادی که از سلامتی برخوردار نیستند، نسبت به افت سلامتی خود احساس نگرانی می نمایم.                                 |   |               |
| 2.  | با دیدن افرادی که از شرایط خوبی برخوردار نیستند، نگران آن می شوم که آینده من نیز همانگونه شود.                             |   |               |
| 3.  | با دیدن افرادی که از شرایط خوبی برخوردار نیستند، نگران آن می شوم که من نیز روش آنها را در پیش گیرم.                        |   |               |
| 4.  | با دیدن افرادی که مشکلاتشان بیشتر از مشکلات من است، از اینکه اوضاع من خیلی خوب پیش می رود، خوشحال می شوم.                  |   |               |
| 5.  | با دیدن افرادی که مشکلاتشان بیشتر از مشکلات من است، از اینکه من وضعیت بهتری دارم، خوشحال می شوم.                           |   |               |
| 6.  | با دیدن افرادی که مشکلاتشان بیشتر از مشکلات من است، متوجه می شوم که وضعیت من چقدر خوب است.                                 |   |               |
| 7.  | با دیدن افرادی که مشکلاتشان کمتر از مشکلات من است، از اینکه می فهمم پیشرفت در زندگی امکان پذیر است، خوشحال می شوم.         |   |               |
| 8.  | با دیدن افرادی که مشکلاتشان کمتر از مشکلات من است، اینکه اوضاع می تواند بهتر شود، مرا خوشحال می کند.                       |   |               |
| 9.  | با دیدن افرادی که مشکلاتشان کمتر از مشکلات من است، به بهبود شرایط خود، بیشتر امیدوار می شوم.                               |   |               |
| 10. | با فکر کردن به افرادی که وضعیت بهتری نسبت به من دارند، اینکه می بینم اوضاع من خیلی خوب پیش نمی رود، برایم تهدید کننده است. |   |               |
| 11. | با فکر کردن به افرادی که وضعیت بهتری نسبت به من دارند، نسبت به شرایط خود، احساس ناامیدی می کنم.                            |   |               |
| 12. | با فکر کردن به افرادی که وضعیت بهتری نسبت به من دارند، اینکه من خیلی خوشبخت نیستم، مرا افسرده می نماید.                    |   |               |

## -The Seizure Severity Scale

پرسشنامه شدت تشنج: SSQ

تاریخ امروز...../...../.....:

نام:.....

پرسشنامه شدت تشنج به بررسی جنبه های گوناگون تشنجات می پردازد. فردی که دچار تشنج می شود، می تواند از برخی افراد مانند خانواده یا دوستانی که این حملات را در وی دیده اند بخواهد تا او را فقط در پاسخ به سوالات مربوط به این اتفاق و نه در رابطه با حالات آن کمک نمایند، زیرا تنها فردی که دچار این حملات می شود از حالات واقعی آن آگاه است

این پرسشنامه شامل 11 سوال در سه بخش و در رابطه با اتفاقاتی که قبل، حین و بعد از هر تشنج روی می دهد، می باشد. لطفا (شایع ترین) بیشترین نوع حمله را برای پاسخگویی به سوالات، در نظر بگیرید. اگر نسبت به پاسخ سوالی اطمینان ندارید، لطفا سعی نمایید بهترین پاسخ خود را داده و توضیحی در کنار آن درج نمایید. در صورت در میان گذاشتن این پرسشنامه با پزشک خود، این یادداشت ها می توانند مفید واقع شوند. پر نمودن این پرسشنامه قبل و بعد از درمان، می تواند به شما و پزشکتان در بررسی تغییرات ایجاد شده بر زندگی شما، کمک نماید

این پرسشنامه توسط [www.epilepsy.com](http://www.epilepsy.com) که پایگاه اطلاعات در مورد بیماری صرع است، تهیه گردیده است.

با آرزوی موفقیت برای شما در زندگی با بیماری صرع!

لطفا در پاسخ دهی به سوالات، عددی را که حالات و احساسات شما را در رابطه با بیشترین نوع حمله به بهترین نحو توصیف می نماید، علامت زده و یا دور آن را خط بکشید. برای مثال: " تا حدی مفید " 4

### حمله از قبل

1. آیا قبل از این نوع حمله، هشداری (حالت قبل از تشنج) همچون بو، احساس، حس و غیره در چهار هفته گذشته داشته اید؟

بله  خیر (اگر پاسخ خیر است به سوال 2 روید)

1 الف. اگر پاسخ بله است، آیا این هشدار (حالت قبل از تشنج)، برای شما مفید بوده است؟ برای مثال، آیا این امکان را به شما داده

است تا خود را برای حمله آماده کنی

1. خیلی مفید بوده است  2 3 4. تا حدی مفید بوده است 5 6 7. مفید نبوده است

حین حمله

2. آیا در چهار هفته گذشته، حرکت و تکان هایی همراه با این نوع حمله (از جمله تکان های غیر ارادی، حرکات غیر قابل کنترل، غش، صدمه، گاز گرفتگی زبان و خیس نمودن خود) داشته اید؟

بله  خیر (اگر پاسخ خیر است به سوال 3 روید)

2 الف) اگر پاسخ بله است، این حرکات و تکان ها تا چه میزان شدید بودند؟

1. خیلی کم 2 3 4. متوسط 5 6 7. خیلی شدید

2 ب) این حرکات و تکان ها در مجموع چقدر مشکل ساز بودند (باعث اختلال در زندگی شما شدند)؟

1. اصلا مشکل ساز نبودند 2 3 4. متوسط 5 6 7. خیلی زیاد

لطفا در پاسخ دهی به سوالات، عددی را که حالات و احساسات شما را در رابطه با بیشترین نوع حمله به بهترین نحو توصیف می نماید، علامت زده و یا دور آن را خط بکشید. برای مثال: "برخی اوقات " 4

3. آیا فقط دچار تغییر در سطح هوشیاری (فراموشی) یا احساسات می شدید؟ هیچ نوع حرکت و یا تکانی همراه با این نوع حمله در چهار هفته گذشته نداشته اید؟

بله  خیر (اگر پاسخ خیر است به سوال 4 روید)

3 الف) اگر پاسخ بله است، این تغییر در سطح هوشیاری چه میزان مشکل ساز بوده است (باعث اختلال در زندگی شما شدند)؟

1. اصلا مشکل ساز نبودند 2 3 4. متوسط 5 6 7. خیلی زیاد

بعد از حمله

4. آیا بعد از این نوع حمله در چهار هفته گذشته، مدت زیادی به طول می انجامید تا بهبود یابید (به زندگی عادی بازگردید)؟

بله  خیر ، بلافاصله بعد از حمله بهبود می یافتم. (اگر پاسخ خیر است، به سوال 8 روید)

5. آیا بعد از این حملات دچار اثرات شناختی (گیجی، از دست دادن حافظه یا عدم تکلم، راه رفتن یا صحبت کردن بی هدف) در چهار هفته گذشته شده اید؟

بله  (اگر پاسخ خیر است، به سوال 6 روید)

5 الف) اگر جواب بله است، هر چند وقت یک بار بعد از هر حمله دچار اثرات شناختی می شدید؟

1. هیچ گاه 2 3 4. برخی اوقات 5 6 7  
همیشه

5 ب) اثرات شناختی بعد از هر حمله تا چه میزان شدید بودند؟

1. خیلی کم 2 3 4. متوسط 5 6 7  
خیلی شدید

5 ج) اثرات شناختی بعد از هر حمله تا چه میزان مشکل ساز بودند؟

1. اصلا مشکل ساز نبودند 2 3 4. متوسط 5 6 7  
خیلی زیاد

6. آیا بعد از هر حمله دچار اثرات عاطفی ( افسردگی، اضطراب، خشم و غیره) می شدید؟

بله  (اگر پاسخ خیر است، به سوال 7 روید)

6 الف) اگر جواب بله است، هر چند وقت یک بار بعد از هر حمله دچار اثرات عاطفی می شدید؟

1. هیچ گاه 2 3 4. برخی اوقات 5 6 7  
همیشه

6 ب) اثرات عاطفی بعد از هر حمله تا چه میزان شدید بودند؟

1. خیلی کم 2 3 4. متوسط 5 6 7  
خیلی شدید

6 ج) اثرات عاطفی بعد از هر حمله تا چه میزان مشکل ساز بودند؟

1. اصلا مشکل ساز نبودند 2 3 4. متوسط 5 6 7  
خیلی زیاد

لطفا در پاسخ دهی به سوالات، عددی را که حالات و احساسات شما را در رابطه با بیشترین نوع حمله به بهترین نحو توصیف می نماید،  علامت زده و یا دور آن را خط بکشید. برای مثال: "متوسط" 4

7. آیا بعد از این حملات دچار اثرات فیزیکی ( خواب آلودگی، خستگی، درد در ماهیچه ها، سر درد)، می شدید؟

بله  (اگر پاسخ خیر است، به سوال 8 روید)

1. هیچ گاه 2 3 4. برخی اوقات 5 6 7  
همیشه

7 الف) اگر جواب بله است، هر چند وقت یک بار بعد از هر حمله دچار اثرات فیزیکی می شدید؟

1. هیچ گاه 2 3 4. برخی اوقات 5 6 7  
همیشه

7 ب) اثرات فیزیکی بعد از هر حمله تا چه میزان شدید بودند؟

1. خیلی کم 2 3 4. متوسط 5 6 7.  
خیلی شدید

7 ج) اثرات فیزیکی بعد از هر حمله تا چه میزان مشکل ساز بودند؟

1. اصلا مشکل ساز نبودند 2 3 4. متوسط 5 6  
7. خیلی زیاد

### ارزیابی کل

احساس خود را نسبت به همه انواع حملاتی که اخیرا داشته اید، بیان نمایید.

8. در مجموع، حملات شما در چهار هفته گذشته تا چه میزان شدید بوده است؟

1. خیلی کم 2 3 4. متوسط 5 6 7.  
خیلی شدید

9. در مجموع، حملات شما در چهار هفته گذشته تا چه میزان مشکل ساز بوده است؟

1. اصلا مشکل ساز نبودند 2 3 4. متوسط 5 6  
7. خیلی زیاد

10. در مجموع، بزرگترین مشکل در حملاتی که به شما دست می دهد چیست؟ ( فقط یک مورد را علامت بزنید).

هشدار ( حالت قبل از تشنج) قبل از حمله

فعالیت ها در طول حمل

بهبود بعد از حمله

فقط در صورت تغییر در درمان حمله، به سوال 11 پاسخ دهید:

11. حملات شما از نظر شدت و مشکل ساز بودن تا چه میزان بعد از درمان، تغییر کرده است؟ ( دور یک عدد خط بکشید)

خیلی بدتر

تغییری نکرده است

خیلی بهتر شده است  
شده است

7-	6-	5-	4-	3-	2-	1-	0	1+	2+	3+	4+	5+	6+	7+
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**Appendix N: Demographics variables in participants of Iran and UK (Study 3)**

		UK	Iran
		Number (%)	Number (%)
Gender	Male	40 (39.8)	46(44.7)
	Female	60(60.2)	57(55.3)
Urine incontinence	Yes	23(23.0)	28(27.2)
	No	77(77.0)	75(72.8)
Age	Mean(SD)	43.28(13.12)	39.74(12.11)
Time since diagnosis	Mean(SD)	20.23(14.84)	14.84(12.81)

**Appendix O: Descriptive Statistics of study variables in participants of**

**UK & Iran (Study 3)**

-The UK

	N	Mean	SD	Skewness	Kurtosis	Kolmogorov-Smirnov	
						Z	P
Total_QOL	100	50.30	18.47	.06	.29	1.10	.17
Anxiety	100	9.980	5.07	-.35	-.77	1.14	.14
Self-esteem	100	16.08	7.31	.03	-.73	.94	.33
Recovery	69	4.75	1.35	-.11	-.44	.55	.91
Activity	70	4.65	1.78	-.50	-.90	1.16	.13
Warning	71	4.14	2.13	.07	-1.31	1.37	.04
Downward_comparison_identification	97	7.75	4.28	.38	-1.30	1.52	.01
Downward_comparison_contrast	97	10.10	3.28	-.39	-.62	1.31	.06
Upward_comparison_identification	97	9.83	3.41	-.31	-.88	1.47	.026
Upward_comparison_contrast	97	8.77	4.01	-.09	-1.29	1.17	.128
Valid N (listwise)	61						

-Iran

	N	Mean	SD	Skewness	Kurtosis	Kolmogorov-Smirnov	
						Z	Z
Total_QOL	103	39.96	20.01	-.36	-.91	1.55	.01
Anxiety	103	12.56	4.16	-.52	-.31	1.16	.13
Self-esteem	103	12.50	6.88	.29	-.90	1.09	.17
Recovery	84	4.58	1.05	-.26	-.04	.89	.39
Activity	85	4.92	1.42	-.72	-.43	1.31	.06
Warning	83	4.40	1.75	-.36	-.79	1.52	.02
Downward_comparison_identification	103	9.42	2.86	.08	-.69	1.39	.04
Downward_comparison_contrast	103	10.92	2.60	-.76	.24	1.77	.004
Upward_comparison_identification	103	10.26	3.13	-.48	-.76	1.49	.02
Upward_comparison_contrast	103	10.70	3.06	-.82	-.19	1.90	.001
Valid N (listwise)	77						

## Appendix P: Regression Analysis (UK study)

**Model Summary<sup>a</sup>**

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate	Change Statistics				
					R Square Change	F Change	df1	df2	Sig. F Change
1	.419 <sup>a</sup>	.176	.115	17.38716	.176	2.878	4	54	.031
2	.643 <sup>b</sup>	.413	.358	14.80843	.237	21.445	1	53	.000
3	.783 <sup>c</sup>	.613	.560	12.25244	.200	13.210	2	51	.000
4	.801 <sup>d</sup>	.642	.558	12.28132	.029	.940	4	47	.449

a. Predictors: (Constant), UI, Age, Gender, Time\_since\_diagnose

b. Predictors: (Constant), UI, Age, Gender, Time\_since\_diagnose, Total\_SSQ

c. Predictors: (Constant), UI, Age, Gender, Time\_since\_diagnose, Total\_SSQ, Anxiety, Self\_esteem

d. Predictors: (Constant), UI, Age, Gender, Time\_since\_diagnose, Total\_SSQ, Anxiety, Self\_esteem, Upward\_comparison\_identification, Downward\_comparison\_contrast, Upward\_comparison\_contrast, Downward\_comparison\_identification

e. Dependent Variable: Total\_QOL

**ANOVA<sup>a</sup>**

Model		Sum of Squares	df	Mean Square	F	Sig.
1	Regression	3480.117	4	870.029	2.878	.031 <sup>a</sup>
	Residual	16324.912	54	302.313		
	Total	19805.029	58			
2	Regression	8182.680	5	1636.536	7.463	.000 <sup>c</sup>
	Residual	11622.349	53	219.290		
	Total	19805.029	58			
3	Regression	12148.788	7	1735.541	11.561	.000 <sup>d</sup>
	Residual	7656.241	51	150.122		
	Total	19805.029	58			
4	Regression	12715.977	11	1155.998	7.664	.000 <sup>e</sup>
	Residual	7089.052	47	150.831		
	Total	19805.029	58			

a. Dependent Variable: Total\_QOL

b. Predictors: (Constant), UI, Age, Gender, Time\_since\_diagnose

c. Predictors: (Constant), UI, Age, Gender, Time\_since\_diagnose, Total\_SSQ

d. Predictors: (Constant), UI, Age, Gender, Time\_since\_diagnose, Total\_SSQ, Anxiety, Self\_esteem

e. Predictors: (Constant), UI, Age, Gender, Time\_since\_diagnose, Total\_SSQ, Anxiety, Self\_esteem, Upward\_comparison\_identification, Downward\_comparison\_contrast, Upward\_comparison\_contrast, Downward\_comparison\_identification



Coefficients <sup>a</sup>											
Model	Unstandardized Coefficients		Standardized Coefficients Beta	t	Sig.	Correlations			Collinearity Statistics		
	B	Std. Error				Zero-order	Partial	Part	Tolerance	VIF	
1	(Constant)	17.519	14.328		1.223	.227					
	Age	.255	.200	.181	1.276	.208	.320	.171	.158	.757	1.320
	Gender	4.350	4.653	.116	.935	.354	.132	.126	.116	.993	1.007
	Time_since_diagnose	.326	.176	.263	1.854	.069	.352	.245	.229	.758	1.320
	UI	4.629	5.428	.106	.853	.398	.094	.115	.105	.989	1.011
2	(Constant)	62.459	15.591		4.006	.000					
	Age	.249	.170	.177	1.463	.149	.320	.197	.154	.757	1.320
	Gender	3.625	3.966	.097	.914	.365	.132	.125	.096	.992	1.008
	Time_since_diagnose	.252	.151	.204	1.676	.100	.352	.224	.176	.749	1.334
	UI	-.644	4.761	-.015	-.135	.893	.094	-.019	-.014	.933	1.072
	Total_SSQ	-7.205	1.556	-.505	-4.631	.000	-.541	-.537	-.487	.930	1.076
3	(Constant)	66.294	16.834		3.938	.000					
	Age	.027	.150	.019	.182	.856	.320	.026	.016	.670	1.492
	Gender	-.130	3.368	-.003	-.039	.969	.132	-.005	-.003	.941	1.062
	Time_since_diagnose	.203	.125	.164	1.621	.111	.352	.221	.141	.741	1.350
	UI	-7.927	4.193	-.181	-1.891	.064	.094	-.256	-.165	.823	1.215
	Total_SSQ	-4.102	1.422	-.288	-2.885	.006	-.541	-.375	-.251	.762	1.312
	Self_esteem	1.121	.347	.444	3.226	.002	.687	.412	.281	.401	2.496
Anxiety	-.646	.494	-.178	-1.307	.197	-.599	-.180	-.114	.411	2.434	
4	(Constant)	69.281	19.825		3.495	.001					
	Age	.023	.153	.016	.147	.884	.320	.021	.013	.642	1.557
	Gender	-.001	3.399	.000	.000	1.000	.132	.000	.000	.928	1.077
	Time_since_diagnose	.168	.128	.135	1.314	.195	.352	.188	.115	.718	1.393
	UI	-8.707	4.744	-.199	-1.835	.073	.094	-.259	-.160	.646	1.548
	Total_SSQ	-4.073	1.584	-.286	-2.571	.013	-.541	-.351	-.224	.617	1.622
	Self_esteem	1.218	.388	.482	3.139	.003	.687	.416	.274	.323	3.099
	Anxiety	-.521	.541	-.143	-.963	.341	-.599	-.139	-.084	.345	2.900
	Downward_comparison_identification	.034	.573	.008	.059	.953	-.485	.009	.005	.430	2.324
	Downward_comparison_contrast	-.912	.613	-.162	-1.486	.144	.113	-.212	-.130	.640	1.563
	Upward_comparison_identification	.725	.570	.134	1.270	.210	.249	.182	.111	.686	1.459
	Upward_comparison_contrast	-.230	.559	-.050	-.411	.683	-.503	-.060	-.036	.515	1.940

a. Dependent Variable: Total\_QOL

## Appendix Q: Regression Analysis (Iran study)

**Model Summary<sup>a</sup>**

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate	Change Statistics				
					R Square Change	F Change	df1	df2	Sig. F Change
1	.399 <sup>a</sup>	.159	.112	18.85938	.159	3.408	4	72	.013
2	.516 <sup>b</sup>	.266	.214	17.74526	.107	10.325	1	71	.002
3	.734 <sup>c</sup>	.539	.493	14.25754	.274	20.493	2	69	.000
4	.784 <sup>d</sup>	.615	.550	13.42788	.076	3.197	4	65	.018

a. Predictors: (Constant), passing\_urine, Gender, Age, Time\_since\_diagnose

b. Predictors: (Constant), passing\_urine, Gender, Age, Time\_since\_diagnose, Total\_SSQ

c. Predictors: (Constant), passing\_urine, Gender, Age, Time\_since\_diagnose, Total\_SSQ, Anxiety, Self\_esteem

d. Predictors: (Constant), passing\_urine, Gender, Age, Time\_since\_diagnose, Total\_SSQ, Anxiety, Self\_esteem, Downward\_comparison\_contrast, Upward\_comparison\_identification, Downward\_comparison\_identification, Upward\_comparison\_contrast

e. Dependent Variable: Total\_QOL

**ANOVA<sup>a</sup>**

Model		Sum of Squares	df	Mean Square	F	Sig.
1	Regression	4848.825	4	1212.206	3.408	.013 <sup>b</sup>
	Residual	25608.689	72	355.676		
	Total	30457.514	76			
2	Regression	8100.028	5	1620.006	5.145	.000 <sup>c</sup>
	Residual	22357.486	71	314.894		
	Total	30457.514	76			
3	Regression	16431.364	7	2347.338	11.547	.000 <sup>d</sup>
	Residual	14026.150	69	203.278		
	Total	30457.514	76			
4	Regression	18737.493	11	1703.408	9.447	.000 <sup>e</sup>
	Residual	11720.021	65	180.308		
	Total	30457.514	76			

a. Dependent Variable: Total\_QOL

b. Predictors: (Constant), passing\_urine, Gender, Age, Time\_since\_diagnose

c. Predictors: (Constant), passing\_urine, Gender, Age, Time\_since\_diagnose, Total\_SSQ

d. Predictors: (Constant), passing\_urine, Gender, Age, Time\_since\_diagnose, Total\_SSQ, Anxiety, Self\_esteem

e. Predictors: (Constant), passing\_urine, Gender, Age, Time\_since\_diagnose, Total\_SSQ, Anxiety, Self\_esteem, Downward\_comparison\_contrast, Upward\_comparison\_identification, Downward\_comparison\_identification, Upward\_comparison\_contrast

Coefficients <sup>a</sup>										
Model	Unstandardized Coefficients		Standardized Coefficients	t	Sig.	Correlations			Collinearity Statistics	
	B	Std. Error	Beta			Zero-order	Partial	Part	Tolerance	VIF
1	(Constant)	40.207	12.711		3.163	.002				
	Age	.359	.181	.218	1.991	.050	.179	.228	.215	.978
	Gender	5.850	4.338	.146	1.349	.182	.147	.157	.146	.996
	Time_since_diagnose	-.241	.174	-.154	-1.381	.171	-.182	-.161	-.149	.939
	passing_urine	-11.592	4.945	-.259	-2.344	.022	-.273	-.266	-.253	.957
2	(Constant)	71.411	15.406		4.635	.000				
	Age	.336	.170	.203	1.977	.052	.179	.228	.201	.976
	Gender	5.482	4.084	.137	1.342	.184	.147	.157	.137	.996
	Time_since_diagnose	-.217	.164	-.139	-1.322	.190	-.182	-.155	-.134	.937
	passing_urine	-10.773	4.660	-.241	-2.312	.024	-.273	-.265	-.235	.955
3	Total_SSQ	-6.945	2.161	-.328	-3.213	.002	-.361	-.356	-.327	.992
	(Constant)	20.465	16.861		1.214	.229				
	Age	.288	.139	.174	2.076	.042	.179	.242	.170	.947
	Gender	.055	3.389	.001	.016	.987	.147	.002	.001	.933
	Time_since_diagnose	-.216	.132	-.138	-1.635	.107	-.182	-.193	-.134	.936
4	passing_urine	-3.178	3.928	-.071	-.809	.421	-.273	-.097	-.066	.867
	Total_SSQ	.003	2.062	.000	.001	.999	-.361	.000	.000	.704
	Anxiety	-.431	.489	-.090	-.882	.381	-.473	-.106	-.072	.645
	Self Esteem	1.765	.325	.607	5.432	.000	.693	.547	.444	.534
	(Constant)	21.575	18.112		1.191	.238				
4	Age	.186	.137	.112	1.358	.179	.179	.166	.104	.864
	Gender	-.064	3.214	-.002	-.020	.984	.147	-.002	-.002	.920
	Time_since_diagnose	-.192	.126	-.123	-1.525	.132	-.182	-.186	-.117	.907
	passing_urine	-.530	3.786	-.012	-.140	.889	-.273	-.017	-.011	.828
	Total_SSQ	-.731	2.140	-.035	-.342	.734	-.361	-.042	-.026	.579
	Anxiety	-.427	.471	-.089	-.907	.368	-.473	-.112	-.070	.617
	Self Esteem	1.710	.335	.588	5.099	.000	.693	.535	.392	.445
	Downward_comparison_identification	.544	.654	.078	.832	.408	-.085	.103	.064	.675
	Downward_comparison_contrast	-1.217	.672	-.158	-1.811	.075	-.036	-.219	-.139	.775
	Upward_comparison_identification	1.523	.593	.238	2.568	.013	.300	.304	.198	.687
Upward_comparison_contrast	-.493	.635	-.075	-.777	.440	-.486	-.096	-.060	.628	

a. Dependent Variable: Total\_QOL

## Appendix R: MANOVA Analysis

Descriptive Statistics				
	groups	Mean	Std. Deviation	N
anxiety	UK	10.8033	4.44530	61
	Iran	13.0909	3.93427	77
	Total	12.0797	4.30593	138
Self_esteem	UK	15.5574	7.05815	61
	Iran	11.5195	6.59667	77
	Total	13.3043	7.07170	138
Downward_comparison_identification	UK	8.3607	4.11919	61
	Iran	9.5455	2.81231	77
	Total	9.0217	3.48818	138
Downward_comparison_contrast	UK	10.0492	3.12744	61
	Iran	11.2468	2.31219	77
	Total	10.7174	2.75784	138
Upward_comparison_identification	UK	9.7541	3.52447	61
	Iran	10.2987	2.98710	77
	Total	10.0580	3.23477	138
Upward_comparison_contrast	UK	8.9672	3.97897	61
	Iran	11.2338	2.71882	77
	Total	10.2319	3.50868	138
Total_QOL	UK	49.5160	16.93361	61
	Iran	37.0029	20.10333	77
	Total	42.5340	19.71496	138
Total_SSQ	UK	4.5386	1.29612	61
	Iran	4.5321	.94559	77
	Total	4.5350	1.10985	138

Levene's Test of Equality of Error Variances <sup>a</sup>				
	F	df1	df2	Sig.
anxiety	1.022	1	136	.314
Self_esteem	.001	1	136	.974
Downward_comparison_identification	18.705	1	136	.000
Downward_comparison_contrast	7.551	1	136	.007
Upward_comparison_identification	3.004	1	136	.085
Upward_comparison_contrast	19.890	1	136	.000
Total_QOL	7.203	1	136	.008
Total_SSQ	10.021	1	136	.002

Tests the null hypothesis that the error variance of the dependent variable is equal across groups.

a. Design: Intercept + groups

Tests of Between-Subjects Effects

Source	Dependent Variable	Type III Sum of Squares	df	Mean Square	F	Sig.	Partial Eta Squared	Noncent. Parameter	Observed Power <sup>a</sup>	
Corrected Model	anxiety	178.120 <sup>a</sup>	1	178.120	10.256	.002	.070	10.256	.889	
	Self_esteem	554.947 <sup>b</sup>	1	554.947	11.987	.001	.081	11.987	.930	
	Downward_comparison_identification	47.778 <sup>c</sup>	1	47.778	4.013	.047	.029	4.013	.512	
	Downward_comparison_contrast	48.814 <sup>d</sup>	1	48.814	6.684	.011	.047	6.684	.728	
	Upward_comparison_identification	10.095 <sup>e</sup>	1	10.095	.964	.328	.007	.964	.164	
	Upward_comparison_contrast	174.853 <sup>f</sup>	1	174.853	15.730	.000	.104	15.730	.976	
	Totall_QOL	5329.358 <sup>g</sup>	1	5329.358	15.125	.000	.100	15.125	.971	
	Totall_SSQ	.001 <sup>h</sup>	1	.001	.001	.973	.000	.001	.050	
	Intercept	anxiety	19432.381	1	19432.381	1118.883	.000	.892	1118.883	1.000
		Self_esteem	24953.875	1	24953.875	539.006	.000	.799	539.006	1.000
Downward_comparison_identification		10912.996	1	10912.996	916.630	.000	.871	916.630	1.000	
Downward_comparison_contrast		15436.003	1	15436.003	2113.746	.000	.940	2113.746	1.000	
Upward_comparison_identification		13686.472	1	13686.472	1307.648	.000	.906	1307.648	1.000	
Upward_comparison_contrast		13889.491	1	13889.491	1249.545	.000	.902	1249.545	1.000	
Totall_QOL		254778.846	1	254778.846	723.082	.000	.842	723.082	1.000	
Totall_SSQ		2800.419	1	2800.419	2256.918	.000	.943	2256.918	1.000	
groups		anxiety	178.120	1	178.120	10.256	.002	.070	10.256	.889
		Self_esteem	554.947	1	554.947	11.987	.001	.081	11.987	.930
	Downward_comparison_identification	47.778	1	47.778	4.013	.047	.029	4.013	.512	
	Downward_comparison_contrast	48.814	1	48.814	6.684	.011	.047	6.684	.728	
	Upward_comparison_identification	10.095	1	10.095	.964	.328	.007	.964	.164	
	Upward_comparison_contrast	174.853	1	174.853	15.730	.000	.104	15.730	.976	
	Totall_QOL	5329.358	1	5329.358	15.125	.000	.100	15.125	.971	
	Totall_SSQ	.001	1	.001	.001	.973	.000	.001	.050	
	Error	anxiety	2362.003	136	17.368					
		Self_esteem	6296.270	136	46.296					
Downward_comparison_identification		1619.156	136	11.906						
Downward_comparison_contrast		993.164	136	7.303						
Upward_comparison_identification		1423.441	136	10.466						
	Upward_comparison_contrast	1511.727	136	11.116						

<b>groups</b>					
Dependent Variable	groups	Mean	Std. Error	95% Confidence Interval	
				Lower Bound	Upper Bound
anxiety	UK	10.803	.534	9.748	11.858
	Iran	13.091	.475	12.152	14.030
Self_esteem	UK	15.557	.871	13.835	17.280
	Iran	11.519	.775	9.986	13.053
Downward_comparison_identification	UK	8.361	.442	7.487	9.234
	Iran	9.545	.393	8.768	10.323
Downward_comparison_contrast	UK	10.049	.346	9.365	10.733
	Iran	11.247	.308	10.638	11.856
Upward_comparison_identification	UK	9.754	.414	8.935	10.573
	Iran	10.299	.369	9.570	11.028
Upward_comparison_contrast	UK	8.967	.427	8.123	9.811
	Iran	11.234	.380	10.482	11.985
Totall_QOL	UK	49.516	2.403	44.763	54.269
	Iran	37.003	2.139	32.773	41.233
Totall_SSQ	UK	4.539	.143	4.257	4.821
	Iran	4.532	.127	4.281	4.783

## Appendix S: Mediation and Moderation (Iran study)

### -Mediation

**Coefficients<sup>a</sup>**

Model	Unstandardized Coefficients		Standardized Coefficients	t	Sig.
	B	Std. Error	Beta		
1 (Constant)	73.957	6.329		11.686	.000
Upward_comparison_contrast	-3.174	.568	-.486	-5.584	.000

a. Dependent Variable: Total\_QOL

**Coefficients<sup>a</sup>**

Model	Unstandardized Coefficients		Standardized Coefficients	t	Sig.
	B	Std. Error	Beta		
1 (Constant)	25.323	2.109		12.005	.000
Upward_comparison_contrast	-1.197	.189	-.532	-6.318	.000

a. Dependent Variable: Self\_esteem

**ANOVA<sup>a</sup>**

Model		Sum of Squares	df	Mean Square	F	Sig.
1	Regression	20431.034	2	10215.517	49.963	.000 <sup>b</sup>
	Residual	20446.156	100	204.462		
	Total	40877.190	102			

a. Dependent Variable: Total\_QOL

b. Predictors: (Constant), Upward\_comparison\_contrast, Self\_esteem

**Coefficients<sup>a</sup>**

Model	Unstandardized Coefficients		Standardized Coefficients	t	Sig.
	B	Std. Error	Beta		
1 (Constant)	29.306	8.016		3.656	.000
Self_esteem	1.763	.243	.607	7.264	.000
Upward_comparison_contrast	-1.063	.546	-.163	-1.948	.054

a. Dependent Variable: Total\_QOL

**-Moderation**

Coefficients <sup>a</sup>						
Model	Unstandardized Coefficients		Standardized Coefficients	t	Sig.	
	B	Std. Error	Beta			
1	(Constant)	39.970	1.394		28.663	.000
	Zscore(Self_esteem)	13.166	1.733	.658	7.595	.000
	Zscore(Downward_comparison_identification)	2.683	1.472	.134	1.822	.071
	Zscore(Downward_comparison_contrast)	-1.080	1.445	-.054	-.748	.457
	Zscore(Upward_comparison_contrast)	-3.016	1.698	-.151	-1.776	.079
2	(Constant)	38.528	1.518		25.380	.000
	Zscore(Self_esteem)	13.390	1.651	.669	8.109	.000
	Zscore(Downward_comparison_identification)	3.728	1.407	.186	2.649	.009
	Zscore(Downward_comparison_contrast)	1.042	1.421	.052	.733	.465
	Zscore(Upward_comparison_contrast)	-2.472	1.608	-.123	-1.539	.127
	ModeratorDI	-4.358	1.343	-.223	-3.245	.002
	ModeratorDC	-4.750	1.336	-.255	-3.554	.001
ModeratorUC	-.970	1.356	-.049	-.716	.476	

a. Dependent Variable: Total\_QOL

ANOVA <sup>a</sup>						
Model		Sum of Squares	df	Mean Square	F	Sig.
1	Regression	21248.130	4	5312.033	26.521	.000 <sup>b</sup>
	Residual	19629.060	98	200.297		
	Total	40877.190	102			
2	Regression	24747.572	7	3535.367	20.823	.000 <sup>c</sup>
	Residual	16129.618	95	169.785		
	Total	40877.190	102			

a. Dependent Variable: Total\_QOL

b. Predictors: (Constant), Zscore(Upward\_comparison\_contrast), Zscore(Downward\_comparison\_contrast), Zscore(Downward\_comparison\_identification), Zscore(Self\_esteem)

c. Predictors: (Constant), Zscore(Upward\_comparison\_contrast), Zscore(Downward\_comparison\_contrast), Zscore(Downward\_comparison\_identification), Zscore(Self\_esteem), ModeratorDI, ModeratorUC, ModeratorDC



## Appendix T: Mediation and Moderation (UK study)

### -Mediation

Model	Unstandardized Coefficients		Standardized Coefficients	t	Sig.
	B	Std. Error	Beta		
(Constant)	63.697	6.962		9.149	.000
Downward_identification	-1.346	.434	-.323	-3.105	.003
1 Downward_contrast	-.156	.528	-.029	-.297	.767
Upward_identification	1.007	.508	.192	1.989	.050
Upward_contrast	-1.302	.465	-.292	-2.799	.006

a. Dependent Variable: Total\_QOL

Model	Sum of Squares	df	Mean Square	F	Sig.
1 Regression	16103.367	5	3220.673	19.990	.000 <sup>b</sup>
Residual	14661.094	91	161.111		
Total	30764.461	96			

a. Dependent Variable: Total\_QOL

b. Predictors: (Constant), Self\_esteem, Upward\_comparison\_identification, Downward\_comparison\_contrast, Downward\_comparison\_identification, Upward\_comparison\_contrast

Model	Unstandardized Coefficients		Standardized Coefficients	t	Sig.
	B	Std. Error	Beta		
(Constant)	31.114	8.216		3.787	.000
Downward_identification	-.543	.398	-.130	-1.364	.176
1 Downward_contrast	-.795	.466	-.146	-1.706	.091
Upward_identification	1.151	.436	.219	2.639	.010
Upward_contrast	-.287	.437	-.064	-.658	.512
Self_esteem	1.409	.244	.574	5.788	.000

a. Dependent Variable: Total\_QOL

## -Moderation

Model Summary

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate	Change Statistics				
					R Square Change	F Change	df1	df2	Sig. F Change
1	.723 <sup>a</sup>	.523	.497	12.69295	.523	19.990	5	91	.000
2	.819 <sup>b</sup>	.670	.636	10.79511	.147	9.702	4	87	.000

a. Predictors: (Constant), Zscore(Upward\_comparison\_contrast), Zscore(Downward\_comparison\_contrast), Zscore(Upward\_comparison\_identification), Zscore(Downward\_comparison\_identification), Zscore(Self\_esteem)

b. Predictors: (Constant), Zscore(Upward\_comparison\_contrast), Zscore(Downward\_comparison\_contrast), Zscore(Upward\_comparison\_identification), Zscore(Downward\_comparison\_identification), Zscore(Self\_esteem), Moderator4, Moderator2, Moderator1, Moderator3

ANOVA<sup>a</sup>

Model		Sum of Squares	df	Mean Square	F	Sig.
1	Regression	16103.367	5	3220.673	19.990	.000 <sup>b</sup>
	Residual	14661.094	91	161.111		
	Total	30764.461	96			
2	Regression	20625.972	9	2291.775	19.666	.000 <sup>c</sup>
	Residual	10138.489	87	116.534		
	Total	30764.461	96			

a. Dependent Variable: Total\_QOL

b. Predictors: (Constant), Zscore(Upward\_comparison\_contrast), Zscore(Downward\_comparison\_contrast), Zscore(Upward\_comparison\_identification), Zscore(Downward\_comparison\_identification), Zscore(Self\_esteem)

c. Predictors: (Constant), Zscore(Upward\_comparison\_contrast), Zscore(Downward\_comparison\_contrast), Zscore(Upward\_comparison\_identification), Zscore(Downward\_comparison\_identification), Zscore(Self\_esteem), Moderator4, Moderator2, Moderator1, Moderator3

Coefficients<sup>a</sup>

Model	Unstandardized Coefficients		Standardized Coefficients	t	Sig.	
	B	Std. Error	Beta			
1	(Constant)	50.333	1.289		39.045	.000
	Zscore(Self_esteem)	10.311	1.782	.574	5.788	.000
	Zscore(Downward_comparison_identification)	-2.328	1.706	-.130	-1.364	.176
	Zscore(Downward_comparison_contrast)	-2.612	1.531	-.146	-1.706	.091
	Zscore(Upward_comparison_identification)	3.929	1.489	.219	2.639	.010
	Zscore(Upward_comparison_contrast)	-1.155	1.754	-.064	-.658	.512
2	(Constant)	47.797	1.373		34.808	.000
	Zscore(Self_esteem)	11.101	1.564	.618	7.099	.000
	Zscore(Downward_comparison_identification)	-2.135	1.533	-.119	-1.393	.167
	Zscore(Downward_comparison_contrast)	-2.988	1.329	-.167	-2.249	.027
	Zscore(Upward_comparison_identification)	3.039	1.282	.170	2.371	.020
	Zscore(Upward_comparison_contrast)	-2.182	1.527	-.122	-1.429	.157
	Moderator1	-1.283	1.480	-.067	-.867	.388
	Moderator2	-3.357	1.363	-.199	-2.464	.016
Moderator3	-3.632	1.269	-.223	-2.861	.005	
Moderator4	-5.477	1.360	-.293	-4.026	.000	

a. Dependent Variable: Total\_QOL

**Appendix U: A Sample of Transcription, and Annotated transcript  
(British participant, Study 1)**

**Participant:** 11

**Interviewer:** A consent form to let you know what's about it.

**Respondent:** Uhm shall I sign?

**Interviewer:** Yeah, here, yeah. Thank you very much.

**Respondent:** And the date is?

**Interviewer:** Today's err, uhm, which date? Twenty-ninth it's true.

**Respondent:** Twenty-ninth.

**Interviewer:** Thank you very much, thanks.

Okay what did you do? How was your weekend, did you enjoy?

**Respondent:** Yeah it was fine thanks. Yeah. Quite a long weekend, with the bank holiday, we just relaxed and everything. My boyfriend had the whole weekend off so we went on some nice walks, Hampstead Heath and everything.

**Interviewer:** That's good, that's good.

**Respondent:** And yourself?

**Interviewer:** Yes, mine was not bad, erm it was good

**Interviewer:** thank you very much for your time,

Shall we start?

**Respondent:** Yeah.

**Interviewer:** May I ask you how old are you?

**Respondent:** I'm 27

**Interviewer:** Ok, when did you diagnosed with epilepsy?

**Respondent:** Uhm, when I was 16.

**Interviewer:** Ok, what happened that time?

**Respondent:** Oh well you know, you don't mind me swearing do you?

**Interviewer:** No problem.

**Respondent:** The usual uhm, I'll swear, can I swear?

**Interviewer:** Yes. Feel free

**Respondent:** The usual ball of shit who uses its mobile while driving.

**Respondent:** And you know is having a chat and driving forty miles an hour.

**Interviewer:** Yeah.

**Respondent:** And he uhm, he hit me uhm, and I was err, you know I was in the coma for a fortnight, very nearly killed and the doctors were saying, "Wow, she's alive," sort of thing. And I remember reading the fits started as soon as I was hit. Yeah, yeah. They were saying my brain was frozen, at The Whittington Hospital and then I went to Great Ormond Street.

**Interviewer:** Yeah.

**Respondent:** Which is rubbish

**Interviewer:** It is no problem it can happen to everyone.

And then after that you were diagnosed with epilepsy?

**Respondent:** Yeah. Immediately after,

**Interviewer:** And before accident, have you had epilepsy?

**Respondent:** No, I was the top of my class, I was known as the, "Maths Queen," because I was so good at maths.

**Interviewer:** Yeah, yeah.

**Respondent:** Uhm, so yeah.

**Interviewer:** That's fine, that's fine. And then okay and feel free, when you want to quit the interview, if you want to stop then no worries.

**Respondent:** No, it's fine, it's fine.

**Interviewer:** And then from that time, like eleven years ago, until now you have epilepsy, don't you?

**Respondent:** Yeah.

**Interviewer:** Could you please explain me about, how is you feeling during your seizure?

**Respondent:** Well at the start of a fits, when I know one is coming on, I do feel a bit, well I do feel significantly anxious. You know like, “Here comes another,” uhm, “Life is rubbish, the day has ended,” sort of thing. Then I will have the fit and if it is a bad one, then I will go unconscious, then that is what happens. I am awake while I am having a fit; I sometimes get suicidal thoughts and everything, so it depends on the fit.

**Interviewer:** Okay, how about your feeling after seizure?

**Respondent:** After fits, I’m unhappy, like the day has all plans down the drain, like yesterday I had one at choir and after it, you know I was a bit shaky and wasn’t up to it and had to go home. So that’s the sort of, you know fits interrupt my day, everything like that. Erm, and when I am not with anyone when I have a fit that is really horrible. I don’t trust humans much because of past experience but I need them with me.

**Interviewer:** Yeah, yeah.

**Respondent:** That affects my independence.

**Interviewer:** Uhum. Can you tell me how?

**Respondent:** Yeah, yeah I hate my life. I often feel quite scared after a fit because I had lots of you know bad experiences in life, like I was also raped five years ago.

**Interviewer:** Oh.

**Respondent:** And I get very scared of people after a fit unless I know them.

**Interviewer:** Okay. Sorry to hear that. Ok, how about your medication? Are you taking them regularly?

**Respondent:** Yeah, I’m taking Lamotrigine, Keppra and Lacosamide and Clobazam

**Interviewer:** When do you get seizure?

**Respondent:** They happen more in the evening, because it’s the end of the day I am quite tired. Then, when, when I got my period, and it becomes worse, yeah that’s it really. So fatigue and, one weird thing is also sad music.

**Interviewer:** Ah does it affect you?

**Respondent:** Lots, strangely enough lots of people say you know, sad music say the violin or a bit of opera, sometimes triggers fits.

**Interviewer:** Uhm, you don’t like it?

**Respondent:** Well the problem is I like classical music. So like Mozart’s Clarinet Concerto.

**Respondent:** I've also tried the, what's that diet called? The one with no carbohydrates? There's some sort of diet that is supposed to reduce fits.

**Respondent:** But I am a vegetarian, so. I have to eat carrots and potato and stuff.

**Interviewer:** Ok, that's fine. Can you tell me what has been changed so far since you diagnosed with epilepsy?

**Respondent:** Everything, I've lost everything in my life

**Interviewer:** Can you give me an example?

**Respondent:** I used to be an independent person, but not anymore... Yeah, Uhm

**Interviewer:** Okay tell me, about your experience of living with epilepsy, I mean what's it like?

**Respondent:** Well it is my worst enemy. I say to the doctor, "It is my worst enemy and I have to live with it twenty-four, seven."

**Interviewer:** Uhm.

**Respondent:** Uhm, because it effects my lifestyle, it ruins so much, I uhm.

**Respondent:** Yeah, so uhm, I, my boyfriend is doing a sponsored skydive for Battersea Dogs and Cats Home but because of epilepsy I can't do it. Uhm, my career, my dream career would be animal rehabilitation but every job I see, says, "Driving licence essential."

**Interviewer:** Yeah.

**Respondent:** I would love to live in the beautiful countryside, but I can't because I don't have a car. It is literally impossible and I can't be as independent as I want to be, like when my boyfriend goes away for a couple of nights, I need one of my family members to come and stay and that can be quite embarrassing. But it, what it most effects is driving, when I see people drive, I become very jealous and I would say, that's what affects me the most. And erm, yeah medication as well, that gets very annoying because of the side effects. Some people don't believe in them, believe there are side effects but if you get talking to some people taking Keppra they'll there's Keppra rage because you get very bad mood swings, because you get very rude to people without wanting to be. Then that causes fatigue and when I was taking Lamotrigine, I was awake for forty-eight hours, it causes insomnia.

**Interviewer:** oh, because of medicine?

**Respondent:** because I take Keppra and that causes fatigue, so it evens out. Uhm but I have, I do have friends who only take Lamotrigine and they say, "Oh I haven't

slept for a three days.” And also erm, pregnancy, I don’t want to be pregnant just yet, until I am properly ready. You know?

**Interviewer:** Uhm.

**Respondent:** But I have many friends who are and it is easy peasy for them, they don’t have to prepare many years in advance like epileptic women do. Uhm, I get very jealous of my sister. Jealousy is key, because I am jealous of people who can drive, can do everything. My sister has got life easy, much easier compared to me and that affects, affects life and yeah, yeah it’s too much part of my life and I think about it every day because it’s associated with everything.

**Interviewer:** Uhm, can you give me an example?

**Respondent:** Yeah, I couldn’t go to choir because I had a fit. I worried about because my boyfriend is going away for four days. Uhm, I need someone to come and be with me and my dog.

**Interviewer:** You don’t like to be stay by yourself?

**Respondent:** No I get very scared, uhm. Very scared of having another fit. I don’t like the fact that fit gonna hits me, I feel really anxious

**Interviewer:** Uhm, can you explain me more?

**Respondent:** Yeah, because like I said, when I, I have fit I get very scared afterwards and then because I don’t trust humans much because of experiences that I had

**Interviewer:** yeah, what else?

**Respondent:** Uhm, if I’m unconscious, which are more frequent these days, I feel ashamed of myself. Like the other day I had a fit at mum’s work and when I woke there was half a banana next to me and I said, “Whose is this?” And my mum said, “My colleague gave you her banana.”

**Respondent:** And I was like, “Oh okay, thank you.”

**Interviewer:** Okay, yeah, how often do you get fit?

**Respondent:** well I get warnings all the time, warnings, yeah fits, probably about three or four a week. To me that is loads and to other people that is nothing.

**Interviewer:** Ok, How is your feeling now?

**Respondent:** It’s got worse; I fall down now a lot. When I was first diagnosed I just had the partial and gradually around about two thousand and ten, I was just having complex, you know and then since I have been collapsing and stuff. Had sort of tonic-clonic



**Respondent:** My face doesn't go blue, I don't need ambulance, but I'll fall, shake and then be unconscious for fifteen minutes say, it's the neurologists don't know why it has got worse.

**Interviewer:** Ok, Can you tell me what bothers you in living with epilepsy?

**Respondent:** Uhm well I guess when people worry too much and they fuss over me and they won't let me continue with what I want to do and therefore make it worse and think, "Well okay the day has ended." I go home, sit down and think that's the day. So I guess over protection bit. Uhm, I was overprotected a lot as a child, for eleven years, you know I couldn't do anything and so I was very, very unhappy. Yeah, I guess that's it, over protection. Uhm, when, I just, the thing about epilepsy is I don't have independence and I want independence and when I am over protected you know, I can't have independence. And, and it's stopped now, but when I was over protected so much during the court case and everything for eleven years, I couldn't do anything without other's permission because of epilepsy and that made it, "Life's a bitch."

**Interviewer:** How freely can you discuss your epilepsy with your friends?

**Respondent:** Partly because I am just so sick and tired of the nation knowing nothing about the condition. You know I was doing salsa once and I had a fit and the next week a woman came to me and said, "Oh what happened to you last week?" And I said, "I had a fit." "A fit?" "Epilepsy." "What's epilepsy?" And I said, "It is the world's most common neurological condition, it's as common as breast cancer, anyone can get it." "Anyone can get it, I can get it?" And I get that a lot, you know? And I just want to tell everyone, "Don't just focus on cancer or the diseases or conditions you think you can get because of what the media says," there are lots more and since epilepsy affects anyone.

**Interviewer:** Yeah, I can understand you. How do you evaluate yourself in interacting socially?

**Respondent:** Well, I go on the Epilepsy Society Forum, it is like Facebook and I talk to people, never meet them but I talk to them. Uhm, I have spoken to a few people actually in the park that I have met that have the condition. My friend Malika, I haven't seen her in a while. Uhm, my mum's colleague sometimes I talk to her, and give her a bit of promising because you know she has only just been diagnosed and she is very scared. Uhm, and yeah, I do speak to people. Our neighbour, my parent's neighbour has epilepsy but she is very fortunate because her medication controls it. She hasn't had one for about three years and so in a year's time will be able to drive.

**Interviewer:** Ok, Do you have anything to add?

**Respondent:** Uhm, the lonely thing is I need my boyfriend. He works full time which is something I don't like much. I would love him to work part time but then at the same time it would probably get very boring for him and so I have to consider him as

well. Sometimes I feel like déjà vue, it is sort of really weird what I get it in the brain and it is hard to explain, I get it in the throat as well, like sometimes it is hard to breath. So I don't want to be alone.

**Interviewer:** Yeah, ok I understand you. So we ran out of time

**Respondent:** Oh, really? I didn't know that

**Interviewer:** No worries. Thank you very much for your time

**Respondent:** Oh you are welcome.

-Annotated transcript

**Participant:** 11    **Nationality:** British    **Gender:**  
Female    **Age:** 27

**Age of diagnose:** 16    **Time since diagnosed:** 11  
years

**Type of epilepsy:** Tonic-clonic seizures

1 **Interviewer:** A consent form to let you know what's  
2 about it.

3 **Respondent:** Uhm shall I sign?

4 **Interviewer:** Yeah, here, yeah. Thank you very  
5 much.

6 **Respondent:** And the date is?

7 **Interviewer:** Today's err, uhm, which date?  
8 Twenty-ninth it's true.

9 **Respondent:** Twenty-ninth.

10 **Interviewer:** Thank you very much, thanks.

11 Okay what did you do? How was your weekend, did  
12 you enjoy?

13 **Respondent:** Yeah it was fine thanks. Yeah. Quite a  
14 long weekend, with the bank holiday, we just relaxed  
15 and everything. My boyfriend had the whole weekend  
16 off so we went on some nice walks, Hampstead Heath  
17 and everything.

18 **Interviewer:** That's good, that's good.

19 **Respondent:** Yeah.

20 **Interviewer:** Okay.

21 **Respondent:** And yourself?

22 **Interviewer:** Yes, mine was not bad, erm it was  
23 good

24 **Interviewer:** thank you very much for your time,  
25 Shall we start?

26 **Respondent:** Yeah.

27 **Interviewer:** May I ask you how old are you?

28 **Respondent:** I'm 27

29 **Interviewer:** Ok, when did you diagnosed with  
30 epilepsy?

31 **Respondent:** Uhm, when I was 16.

32 **Interviewer:** Ok, what happened that time?  
33 **Respondent:** Oh well you know, you don't mind me  
34 swearing do you?  
35 **Interviewer:** No problem.  
36 **Respondent:** The usual uhm, I'll swear, can I swear?  
37 **Interviewer:** Yes. Feel free  
38 **Respondent:** The usual ball of shit who uses its  
39 mobile while driving.  
40 **Respondent:** And you know is having a chat and  
41 driving forty miles an hour.  
42 **Interviewer:** Yeah.  
43 **Respondent:** And he uhm, he hit me uhm, and I was  
44 err, you know I was in the coma for a fortnight, very  
45 nearly killed and the doctors were saying, "Wow,  
46 she's alive," sort of thing. And I remember reading  
47 the fits started as soon as I was hit. Yeah, yeah. They  
48 were saying my brain was frozen, at The Whittington  
49 Hospital and then I went to Great Ormond Street.  
50 **Interviewer:** Yeah.  
51 **Respondent:** Which is rubbish  
52 **Interviewer:** It is no problem it can happen to  
53 everyone. And then after that you were diagnosed  
54 with epilepsy?  
55 **Respondent:** Yeah. Immediately after,  
56 **Interviewer:** And before accident, have you had  
57 epilepsy?  
58 **Respondent:** No, I was the top of my class, I was  
59 known as the, "Maths Queen," because I was so good  
60 at maths.  
61 **Interviewer:** Yeah, yeah.  
62 **Respondent:** Uhm, so yeah.

*feeling bad*

*Seizure  
experience*

*Experience*

*good experience before  
epilepsy*

63 **Interviewer:** That's fine, that's fine. And then okay  
64 and feel free, when you want to quit the interview, if  
65 you want to stop then no worries.

66 **Respondent:** No, it's fine, it's fine.

67 **Interviewer:** And then from that time, like eleven  
68 years ago, until now you have epilepsy, don't you?

69 **Respondent:** Yeah.

70 **Interviewer:** Could you please explain me about,  
71 how is you feeling during your seizure?

"Seizure impact"  
Anxiety

72 **Respondent:** Well at the start of a fits, when I know  
73 one is coming on, I do feel a bit, well I do feel  
74 significantly anxious. You know like, "Here comes  
75 another," uhm, "Life is rubbish, the day has ended,"  
76 sort of thing. Then I will have the fit and if it is a bad  
77 one, then I will go unconscious, then that is what  
78 happens. I am awake while I am having a fit; I  
79 sometimes get suicidal thoughts and everything, so it  
80 depends on the fit.

feeling anxious  
before going to  
Seizure  
Bad expression  
Negative thought

81 **Interviewer:** Okay, how about your feeling after  
82 seizure?

83 **Respondent:** After fits, I'm unhappy, like the day  
84 has all plans down the drain, like yesterday I had one  
85 at choir and after it, you know I was a bit shaky and  
86 wasn't up to it and had to go home. So that's the sort  
87 of, you know fits interrupt my day, everything like  
88 that. Erm, and when I am not with anyone when I  
89 have a fit that is really horrible. I don't trust humans  
90 much because of past experience but I need them with  
91 me.

"Seizure  
impact"

Feeling Bad, negative  
expression after fit

Impact of seizure  
Feeling not good  
Lack of trust

92 **Interviewer:** Yeah, yeah.

loss of independence

93 **Respondent:** That affects my independence.

Negative impact of seizure

94 **Interviewer:** Uhm. Can you tell me how?

95 **Respondent:** Yeah, yeah I hate my life. I often feel  
96 quite scared after a fit because I had lots of you know  
97 bad experiences in life, like I was also raped five  
98 years ago.

-Bad feeling's hatred  
toward life  
-Negative feeling  
Feeling scared

4 -Bad experience



99 **Respondent:** And I get very scared of people after a  
100 fit unless I know them. *lack of trust to people  
feeling insecure*

101 **Interviewer:** Okay. Sorry to hear that. Ok, how  
102 about your medication? Are you taking them  
103 regularly?

104 **Respondent:** Yeah, I'm taking Lamotrigine, Keppra  
105 and Lacosamide and Clobazam *on medication*

*"perceived triggers"* 106 **Interviewer:** When do you get seizure?  
*possible trigger* 107 **Respondent:** They happen more in the evening,  
108 because it's the end of the day I am quite tired. Then,  
109 when, when I got my period, and it becomes worse,  
110 yeah that's it really. So fatigue and, one weird thing  
111 is also sad music. *Causal belief  
Causal belief  
triggers*

112 **Interviewer:** Ah does it affect you?

*triggers* 113 **Respondent:** Lots, strangely enough lots of people  
114 say you know, sad music say the violin or a bit of  
115 opera, sometimes triggers fits. *attribution  
Potential trigger*

116 **Interviewer:** Uhm, you don't like it?

117 **Respondent:** Well the problem is I like classical  
118 music. So like Mozart's Clarinet Concerto. *Feeling good about  
music*

119 **Respondent:** I've also tried the, what's that diet  
120 called? The one with no carbohydrates? There's  
121 some sort of diet that is supposed to reduce fits.

122 **Respondent:** But I am a vegetarian, so, I have to eat  
123 carrots and potato and stuff. *explanation for  
eating diet*

124 **Interviewer:** Ok, that's fine. Can you tell me what  
125 has been changed so far since you diagnosed with  
126 epilepsy?

127 **Respondent:** Everything, I've lost everything in my  
128 life *Negative expression*

*loss of independence* 129 **Interviewer:** Can you give me an example?  
130 **Respondent:** I used to be an independent person, but  
131 not anymore... Yeah, Uhm *Comparison to past  
feeling negative now  
lack of independency*

132 **Interviewer:** Okay tell me, about your experience of  
133 living with epilepsy, I mean what's it like?

upward  
negative  
comparison

134 **Respondent:** Well it is my worst enemy, I say to the  
135 doctor, "It is my worst enemy and I have to live with  
136 it twenty-four, seven." Uhm, because it effects my  
137 lifestyle, it ruins so much, I uhm. Yeah, so uhm, I, my  
138 boyfriend is doing a sponsored skydive for Battersea  
139 Dogs and Cats Home but because of epilepsy I can't  
140 do it. Uhm, my career, my dream career would be  
141 animal rehabilitation but every job I see, says,  
142 "Driving licence essential,"

Negative expression  
negative feeling  
comparison to boyfriend  
& feeling negative  
future inspiration  
potential limitation

143 **Interviewer:** Yeah.

loss of  
independence

"negative  
upward  
comparison"

"Percent triggers"

Medication  
attributions

mood  
swing

lack of  
sleep

144 **Respondent:** I would love to live in the beautiful  
145 countryside, but I can't because I don't have a car, It  
146 is literally impossible, and I can't be as independent as  
147 I want to be, like when my boyfriend goes away for a  
148 couple of nights, I need one of my family members to  
149 come and stay and that can be quite embarrassing.  
150 But it, what it most effects is driving, when I see  
151 people drive, I become very jealous and I would say,  
152 that's what affects me the most.

having desire  
lack of something  
feeling negative  
not being independent  
Need care  
Embarrassment  
Feeling Envy - negative  
explanation in comparison  
Some one driving

153 **Respondent:** And erm, yeah medication as well, that  
154 gets very annoying because of the side effects. Some  
155 people don't believe in them, believe there are side  
156 effects but if you get talking to some people taking  
157 Keppra they'll there's Keppra rage because you get  
158 very bad mood swings, because you get very rude to  
159 people without wanting to be. Then that causes  
160 fatigue and when I was taking Lamotrigine, I was  
161 awake for forty-eight hours, it causes insomnia.

Medication side effect  
attribution to others  
negative explanation of  
medicine  
lack of control  
Medication side effect.

162 **Interviewer:** oh, because of medicine?

163 **Respondent:** because I take Keppra and that causes  
164 fatigue, so it evens out. Uhm but I have, I do have  
165 friends who only take Lamotrigine and they say, "Oh  
166 I haven't slept for a three days." And also erm,  
167 pregnancy, I don't want to be pregnant just yet, until I  
168 am properly ready. You know?

Causal belief  
Negative explanation  
about future



"upward  
negative  
comparison"

169 **Respondent:** But I have many friends who are and it  
170 is easy peasy for them, they don't have to prepare  
171 many years in advance like epileptic women do.  
172 Uhm, I get very jealous of my sister. Jealousy is key,  
173 because I am jealous of people who can drive, can do  
174 everything. My sister has got life easy, much easier  
175 compared to me and that affects, affects life and yeah,  
176 yeah it's too much part of my life and I think about it  
177 every day because it's associated with everything.

Negative feeling  
in comparison to others

Sibling jealousy  
Negative thought toward  
these who driving  
comparison

"Seizure impact"  
Fear  
anxiety

178 **Interviewer:** Uhm, can you give me an example?

179 **Respondent:** Yeah, I couldn't go to choir because I  
180 had a fit. I worried about because my boyfriend is  
181 going away for four days. Uhm, I need someone to  
182 come and be with me and my dog.

Feeling worry  
Not willing to stay  
or love

183 **Interviewer:** You don't like to be stay by yourself?

Fear  
Anxiety

184 **Respondent:** No I get very scared, uhm. Very scared  
185 of having another fit. I don't like the fact that fit  
186 gonna hits me, I feel really anxious

Fear of being alone  
fear of next seizure  
Not happy with life  
Feeling worry

187 **Interviewer:** Uhm, can you explain me more?

188 **Respondent:** Yeah, because like I said, when I, I  
189 have fit I get very scared afterwards and then because  
190 I don't trust humans much because of experiences that  
191 I had

feeling fearful  
lack of trust

192 **Interviewer:** yeah, what else?

Embarrassment

193 **Respondent:** Uhm, if I'm unconscious, which are  
194 more frequent these days, I feel ashamed of myself.  
195 Like the other day I had a fit at mum's work and when  
196 I woke there was half a banana next to me and I said,  
197 "Whose is this?" And my mum said, "My colleague  
198 gave you her banana."

explanation for seizure  
Humiliation

Feeling blushed

199 **Respondent:** And I was like, "Oh okay, thank you."

200 **Interviewer:** Okay, yeah. How often do you get fit?

Comparison

201 **Respondent:** well I get warnings all the time,  
202 warnings, yeah fits, probably about three or four a  
203 week. To me that is loads and to other people that is  
204 nothing.

Experience of having seizure  
times happening  
comparison to others

205 **Interviewer:** Ok, How is your feeling now?

206 **Respondent:** It's got worse; I fall down now a lot. *Seizure influence* *Seizure explained*

207 When I was first diagnosed I just had the partial and *initial experience*

208 gradually around about two thousand and ten, I was

209 just having complex, you know and then since I have *type of seizure*

210 been collapsing and stuff. Had sort of tonic-clonic

211 **Respondent:** My face doesn't go blue, I don't need *physical expression*

212 ambulance, but I'll fall, shake and then be

213 unconscious for fifteen minutes say, it's the *Duration for seizure*

214 neurologists don't know why it has got worse.

215 **Interviewer:** Ok, Can you tell me what bothers you

216 in living with epilepsy?

217 **Respondent:** Uhm well I guess when people worry *"Negative consequence of living with Epilepsy"* *other feeling on*

218 too much and they fuss over me and they won't let me *too much attention*

219 continue with what I want to do and therefore make it

220 worse and think, "Well okay the day has ended." I go *negative expression*

221 home, sit down and think that's the day. So I guess

222 over protection bit. Uhm, I was overprotected a lot as *excessive support*

223 a child, for eleven years, you know I couldn't do *lack of autonomy*

224 anything and so I was very, very unhappy. Yeah, I

225 guess that's it, over protection.

226 **Interviewer:** Ok

227 **Respondent:** Uhm, when, I just, the thing about *loss of independence* *Experience of living with Epilepsy*

228 epilepsy is I don't have independence and I want *lack of independence*

229 independence and when I am over protected you *feeling overprotected*

230 know, I can't have independence. And, and it's

231 stopped now, but when I was over protected so much

232 during the court case and everything for eleven years,

233 I couldn't do anything without other's permission *Feeling unhappy*

234 because of epilepsy and that made it, "Life's a bitch." *Swearing*

235 **Interviewer:** How freely can you discuss your

236 epilepsy with your friends?

237 **Respondent:** Partly because I am just so sick and *perception of stigma* *Negative feeling toward others*

238 tired of the nation knowing nothing about the *explaining experience*

239 condition. You know I was doing salsa once and I

240 had a fit and the next week a woman came to me and

241 said, "Oh what happened to you last week?" And I

242 said, "I had a fit." "A fit?" "Epilepsy." "What's

243 epilepsy?" And I said, "It is the world's most  
244 common neurological condition, it's as common as  
245 breast cancer, anyone can get it." "Anyone can get it,  
246 I can get it?" And I get that a lot, you know? And I  
247 just want to tell everyone, "Don't just focus on cancer  
248 or the diseases or conditions you think you can get  
249 because of what the media says," there are lots more  
250 and since epilepsy affects anyone.

Perception of  
stigma

Negative feeling  
Negative social  
interaction  
Lack of understanding

251 **Interviewer:** Yeah, I can understand you

252 **Interviewer:** How do you evaluate yourself in  
253 interacting socially?

254 **Respondent:** Well, I go on the Epilepsy Society  
255 Forum, it is like Facebook and I talk to people, never  
256 meet them but I talk to them. Uhm, I have spoken to  
257 a few people actually in the park that I have met that  
258 have the condition. My friend Malika, I haven't seen  
259 her in a while. Uhm, my mum's colleague sometimes  
260 I talk to her, and give her a bit of promising because  
261 you know she has only just been diagnosed and she is  
262 very scared. Uhm, and yeah, I do speak to people.  
263 Our neighbour, my parent's neighbour has epilepsy  
264 but she is very fortunate because her medication  
265 controls it. She hasn't had one for about three years  
266 and so in a year's time will be able to drive.

"upward  
negative  
comparison"

Social interactions  
Feeling comparison  
to others in good  
position than herself

267 **Interviewer:** Ok. Do you have anything to add?

268 **Respondent:** Uhm, the lonely thing is I need my  
269 boyfriend. He works full time which is something I  
270 don't like much. I would love him to work part time  
271 but then at the same time it would probably get very  
272 boring for him and so I have to consider him as well.  
273 Sometimes I feel like déjà vue, it is sort of really  
274 weird what I get it in the brain and it is hard to  
275 explain, I get it in the throat as well, like sometimes it  
276 is hard to breath. So I don't want to be alone.

Fear

Need to be with  
having familiar feeling  
before seizure  
Not willing to be alone

277 **Interviewer:** Yeah, ok I understand you. So we ran  
278 out of time

279 **Respondent:** Oh, really? I didn't know that

**Appendix V: A Sample of Transcription, and Annotated transcript  
(Iranian participant, Study 1)**

**Participant:** 5

**Interviewer:** Thanks for your time

**Respondent:** No problem

**Interviewer:** Could you please tell me how old are you?

**Respondent:** I am 50.

**Interviewer:** ok

**Interviewer:** When you were diagnosed with epilepsy?

**Respondent:** I was 22 years old

**Interviewer:** Ok. what type of epilepsy do you have?

**Respondent:** I have photosensitive epilepsy

**Interviewer:** Ok. Can you explain to me what your feeling was when you first diagnosed with epilepsy?

**Respondent:** I was single, and I remember I had a terrible cold, I had high fever and my dad was looking after me. But suddenly my body started to shake and I couldn't see anything I thought it was happen because of fever, but later my dad took me to hospital. It was Eid time and we couldn't find any good doctor, they kept me there for couple of days, and later I remember I got another seizure. But this time I hadn't had any cold or fever. After that doctor came and had some scans and later we were told that I have epilepsy. At the beginning I didn't know what it is, but then I noticed that my God it has got lots of difficulties which you don't have any other choice to take, you should live with it for the rest of your life.

**Interviewer:** Ok I know what you mean. How often do you get seizure?

**Respondent:** not that much really, I think my medication is good and it has controlled my seizures well. The last one was about a year ago, since then I haven't got any seizure.



**Interviewer:** ok that's good. After seizure, what's your feeling? How do you find yourself? Even though you haven't got it for a year.

**Respondent:** yeah, Uhm, I'm not sure really, but as a man it's difficult, very difficult. Because I'm very sensitive to lights, even at home I have to watch myself to not stay in too much bright room. This is something that bothers my children

**Interviewer:** How many children do you have?

**Respondent:** 3, yeah so I remember the last one which happen last year, it was my son's birthday. So it was really bad, I was ashamed of myself, and I'm sure my son a well. His friends all of them were at our home, and suddenly I got seizure and apparently when I'm going to seizure I'm staring at some point which is really annoying. On top of that I wet myself afterwards.

**Interviewer:** oh, you pass urine? Only during a seizure?

**Respondent:** yeah only during a seizure, which is really embarrassing as a man I'm not that much old, like an old man. It was an awful experience, it just pushes me to feel nerves in front of others, even my wife. In that party my wife got embarrassed too, I think because she had to change my trouser. I've to say, actually whoever was there was shocked. Yeah I never forget that day, it was a big day for me but I ruined the party, and I never forgive myself

**Interviewer:** oh don't say that, it can happen to anyone, are you happy to continue? Feel free if you want to stop it

**Respondent:** no I can talk don't worry.

**Interviewer:** Ok, Do you take your medicine regularly?

**Respondent:** yes of course, I never forget, but even if I forget, my children specially my son remind me to take it

**Interviewer:** Ok it's good. Can you tell me what it is like living with epilepsy?

**Respondent:** for me is really difficult, because the only breadwinner at home is me, my wife is housewife. I used to have a good job indeed.

**Interviewer:** What was happen then?

**Respondent:** I used to work for a company, I was a sale manager. I had never told them before about my epilepsy. Once I got seizure at office, because I had to much work to do, and I think that caused me to get seizure and everyone noticed. It was very embarrassing. It wasn't nice to be seen as a person who staring at some point. So, one month later, I received a letter which was my termination of contract. They didn't keep me as an employee anymore. It was a big shock for me, I couldn't accept the fact that

I don't have any job. Then for me it took a long time to get another job and I'm not employee anymore

**Interviewer:** do you mind if I ask you what your job is now?

**Respondent:** no, I'm a taxi driver. I used to have a good life style but now everything has changed

**Respondent:** the bad point is, the company took me out of their contract, because of my epilepsy; and now I don't have life insurance, and I don't have job either, which is quite threatening. My wife and my children they are under my responsibility and now they are not insured. We also don't receive any financial support from health organisations, which is really awful. I have to handle everything on my own

**Interviewer:** yeah I know. May I ask you why you didn't tell your company? I mean was there something that you didn't want to let them know.

**Respondent:** I know what you mean. I couldn't say from the beginning because you know better than me that in our society no one accepts a person who has epilepsy. Especially in work environment no one wants to pay to someone ill. So that's why I did my best to hide it. Even when I was taking my medicines, if someone was seeing me, I was pretending that this is just a simple ibuprofen because of headache. I never let them to know but this is my luck

**Interviewer:** I can understand you

**Respondent:** but still my family are not happy with my job, they always blame me about my job, they don't like it. But what should I do? I do need money to take to home and have to afford my life. I'm in conflict with my wife, she always complaining me and pushing me to change my job, but the thing is no one going to give a good job for me, because in the letter it was written that because of epilepsy he cannot be able to continue this job

**Interviewer:** I know, I can understand you. Are there any other things that are important to you for living with epilepsy?

**Respondent:** Uhm, people's attitudes is really important. Since I've lost my job everything has changed to me. I feel really down and silly, who was unable to keep his job secure

**Interviewer;** No don't think like that, this could happen to anyone

**Respondent:** yeah, I know but still I feel like why me? Even I feel nervous in social gathering, I don't like to be any event now, because I really worry to get seizure and ruin the party, like I did last year. The other day I was talking to my doctor and he said that you should be happy now you haven't get seizure for a year but I said no doctor,

it may happen now, it may happen tomorrow and I have no idea what I need to do. It's like a mental battle in your mind , and you can't get rid of it

**Interviewer;** Yeah, how often do you have freely discussion about your epilepsy with your friends?

**Respondent:** friend?! (laughing) even my wife is not happy with me, how can I expect someone to be nice with me. I don't have that much friend. I used to have good friend in company when I was there, we used to go lunch every Monday it was really nice group. But since they notice that I've epilepsy they didn't talk to me anymore. It's just like your losing your friends when you have illness

**Interviewer:** Yeah I can understand you.

**Interviewer:** Can you tell me what has been changed since you got epilepsy?

**Respondent:** Uhm, lots of things have changed since then. My personality changed to be a person who always scared, uhm, scared of getting seizure in public place, or even small family parties. I've changed to a person who has not any respect in society, because of not having a proper job. Yeah, everything has changed. I used to do all my shopping on my own, now I need my son or my wife to be with me while I do shopping. I'm not that much independent as it used to be. Because I feel if something happen at least I can have my family besides me.

**Interviewer:** Ok. Thank you very much for your time giving me

**Respondent:** no worries thanks to talk to me, I feel much better now. At least you are educated and I don't feel really shy in front of you

**Interviewer:** you're welcome

-Annotated transcript

**Participant:** 5      **Nationality:** Iranian      **Gender:**  
Male

**Age:** 50      **Age of diagnose:** 22      **Time since**  
**diagnosed:** 28years

**Type of epilepsy:** Photosensitive epilepsy



1 **Interviewer:** Thanks for your time  
2 **Respondent:** no problem  
3 **Interviewer:** Could you please tell me how old are you?  
4 **Respondent:** I am 50.  
5 **Interviewer:** ok  
6 **Interviewer:** When you were diagnosed with epilepsy?  
7 **Respondent:** I was 22 years old  
8 **Interviewer:** Ok. what type of epilepsy do you have?  
9 **Respondent:** I have photosensitive epilepsy  
10 **Interviewer:** Ok. Can you explain to me what your feeling  
11 was when you first diagnosed with epilepsy?  
12 **Respondent:** I was single, and I remember I had a terrible  
13 cold, I had high fever and my dad was looking after me. But  
14 suddenly my body started to shake and I couldn't see  
15 anything I thought it was happen because of fever, but later  
16 my dad took me to hospital. It was Eid time and we couldn't  
17 find any good doctor, they kept me there for couple of days,  
18 and later I remember I got another seizure. But this time I  
19 hadn't had any cold or fever. After that doctor came and  
20 had some scans and later we were told that I have epilepsy.  
21 At the beginning I didn't know what it is, but then I noticed  
22 that my God it has got lots of difficulties which you don't  
23 have any other choice to take, you should live with it for the  
24 rest of your life.  
25 **Interviewer:** Ok I know what you mean. How often do you  
26 get seizure?

re: ever  
impact

Epilepsy type

Beginning of  
Epilepsy

Seizure experier

overlapping the  
events

The experience  
of diagnosing  
with Epilepsy

Feeling helpless.  
Feeling obliged

27 **Respondent:** not that much really, I think my medication is  
28 good and it has controlled my seizures well. The last one  
29 was about a year ago, since then I haven't got any seizure.

Seizure is  
controlled  
time of last  
seizure

30 **Interviewer:** ok that's good. After seizure, what's your  
31 feeling? How do you find yourself? Even though you  
32 haven't got it for a year.

perceived  
triggers

33 **Respondent:** yeah, Uhm, I'm not sure really, but as a man  
34 it's difficult, very difficult. Because I'm very sensitive to  
35 lights, even at home I have to watch myself to not stay in  
36 too much bright room. This is something that bothers my  
37 children

Feeling negative  
Causal belief  
Embarrassing

38 **Interviewer:** How many children do you have?

39 **Respondent:** 3, yeah so I remember the last one which  
40 happen last year, it was my son's birthday. So it was really  
41 bad, I was ashamed of myself, and I'm sure my son a well.  
42 His friends all of them were at our home, and suddenly I got  
43 seizure and apparently when I'm going to seizure I'm  
44 staring at some point which is really annoying. On top of  
45 that I wet myself afterwards.

Negative experience  
of getting seizure  
Humiliation  
Physical express  
during seizure  
Passing urine

Urinary  
incontinence

46 **Interviewer:** oh, you pass urine? Only during a seizure?

47 **Respondent:** yeah only during a seizure, which is really  
48 embarrassing as a man I'm not that much old, like an old  
49 man. It was an awful experience, it just pushes me to feel  
50 nerves in front of others, even my wife. In that party my  
51 wife got embarrassed too, I think because she had to change  
52 my trouser. I've to say, actually whoever was there was  
53 shocked. Yeah I never forget that day, it was a big day for  
54 me but I ruined the party, and I never forgive myself

Passing urine during  
seizure → attrib  
- Embarrassment  
- Negative express  
- feeling nerves  
to retire  
- others' embarrass  
↳ feeling ashamed  
Feeling blamed - by  
the self

Urinary  
incontinence  
Anxiety

55 **Interviewer:** oh don't say that, it can happen to anyone, are  
56 you happy to continue? Feel free if you want to stop it

Shameful self

57 **Respondent:** no I can talk don't worry.

58 **Interviewer:** Ok, Do you take your medicine regularly?

59 **Respondent:** yes of course, I never forget, but even if I  
60 forget, my children specially my son remind me to take it

*taking medicine*

61 **Interviewer:** Ok it's good. Can you tell me what it is like  
62 living with epilepsy?

63 **Respondent:** for me is really difficult, because the only  
64 breadwinner at home is me, my wife is housewife. I used to  
65 have a good job indeed.

*Challenging time  
limited income*

66 **Interviewer:** What was happen then?

*~ Perception  
of  
stigma  
~ Experience of  
employment  
~ Perceived  
triggers  
Negative experience  
of employment*

67 **Respondent:** I used to work for a company, I was a sale  
68 manager. I had never told them before about my epilepsy.  
69 Once I got seizure at office, because I had to much work to  
70 do, and I think that caused me to get seizure and everyone  
71 noticed. It was very embarrassing. It wasn't nice to be seen  
72 as a person who staring at some point. So, one month later, I  
73 received a letter which was my termination of contract.  
74 They didn't keep me as an employee anymore. It was a big  
75 shock for me, I couldn't accept the fact that I don't have any  
76 job. Then for me it took a long time to get another job and  
77 I'm not employee anymore

*negative  
experience of ep  
hide the illness  
Causal beliefs  
Humiliation  
Embarrassment  
Leaving the job  
difficult to  
accept  
losing the job  
negative express*

78 **Interviewer:** do you mind if I ask you what your job is  
79 now?

80 **Respondent:** no, I'm a taxi driver. I used to have a good  
81 life style but now everything has changed

*Experience of  
employment  
Insufficient  
financial  
support*

82 **Respondent:** the bad point is, the company took me out of  
83 their contract, because of my epilepsy; and now I don't have  
84 life insurance, and I don't have job either, which is quite  
85 threatening. My wife and my children they are under my

*Correct job  
changing in life  
style because  
of epilepsy  
Lack of insurance  
Living difficult  
Feeling shaky &  
Unstable*

5



Insufficient financial support

86 responsibility and now they are not insured. We also don't  
87 receive any financial support from health organisations,  
88 which is really awful. I have to handle everything on my  
89 own

Lack of financial support  
negative feelings  
expression towards  
insufficient financial support

90 **Interviewer:** yeah I know. May I ask you why you didn't  
91 tell your company? I mean was there something that you  
92 didn't want to let them know.

perception of stigma

93 **Respondent:** I know what you mean. I couldn't say from  
94 the beginning because you know better than me that in our  
95 society no one accepts a person who has epilepsy.  
96 Especially in work environment no one wants to pay to  
97 someone ill. So that's why I did my best to hide it. Even  
98 when I was taking my medicines, if someone was seeing  
99 me, I was pretending that this is just a simple ibuprofen  
100 because of headache. I never let them to know but this is my  
101 luck

Negative impressions  
in society  
Bad perspective  
society towards  
epilepsy  
keeping secret  
not letting others  
know

102 **Interviewer:** I can understand you

Insufficient financial support

103 **Respondent:** but still my family are not happy with my job,  
104 they always blame me about my job, they don't like it. But  
105 what should I do? I do need money to take to home and  
106 have to afford my life. I'm in conflict with my wife, she  
107 always complaining me and pushing me to change my job,  
108 but the thing is no one going to give a good job for me,  
109 because in the letter it was written that because of epilepsy  
110 he cannot be able to continue this job

negative feeling  
family members  
others bad experience  
on him  
financial issue  
not good in marriage  
feeling bad about future

perception of stigma

111 **Interviewer:** I know, I can understand you. Are there any  
112 other things that are important to you for living with  
113 epilepsy?

114 **Respondent:** Uhm, people's attitudes is really important.  
115 Since I've lost my job everything has changed to me. I feel

importance of  
others view on  
self  
change in life

116 really down and silly, who was unable to keep his job  
117 secure

Embarrassment

118 **Interviewer:** No don't think like that, this could happen to  
119 anyone

120 **Respondent:** yeah, I know but still I feel like why me?

Anxiety

121 Even I feel nervous in social gathering, I don't like to be  
122 any event now, because I really worry to get seizure and  
123 ruin the party, like I did last year. The other day I was  
124 talking to my doctor and he said that you should be happy  
125 now you haven't get seizure for a year but I said no doctor,  
126 it may happen now, it may happen tomorrow and I have no  
127 idea what I need to do. It's like a mental battle in your mind  
128 , and you can't get rid of it

Search for meaning  
Anxiety impact  
Not willing to social  
feeling anxious because of seizure  
unexpected seizure impact  
Fear of next seizure  
Feeling occupied

Fear

129 **Interviewer:** Yeah, how often do you have freely  
130 discussion about your epilepsy with your friends?

Perception of stigma

131 **Respondent:** friend?! (laughing) even my wife is not happy  
132 with me, how can I expect someone to be nice with me. I  
133 don't have that much friend. I used to have good friend in  
134 company when I was there, we used to go lunch every  
135 Monday it was really nice group. But since they notice that  
136 I've epilepsy they didn't talk to me anymore. It's just like  
137 your losing your friends when you have illness

Negative experience toward family  
negative social interaction  
Feeling alone  
positive feeling from past life  
negative view on epilepsy

138 **Interviewer:** Yeah I can understand you.

139 **Interviewer:** Can you tell me what has been changed since  
140 you got epilepsy?

Fear

141 **Respondent:** Uhm, lots of things have changed since then.  
142 My personality changed to be a person who always scared,  
143 uhm, scared of getting seizure in public place, or even small  
144 family parties. I've changed to a person who has not any  
145 respect in society, because of not having a proper job. Yeah,

Fear

Fearful  
Fear of seizure  
Fear of being in public  
Shameful self

loss of independence

146 everything has changed. I used to do all my shopping on my  
147 own, now I need my son or my wife to be with me while I  
148 do shopping. I'm not that much independent as it used to be.  
149 Because I feel if something happen at least I can have my  
150 family besides me.

was able to  
ordinary task in  
the past  
need protection  
lack of independ  
fearful

151 **Interviewer:** Ok. Thank you very much for your time  
152 giving me

153 **Respondent:** no worries thanks to talk to me, I feel much  
154 better now. At least you are educated and I don't feel really  
155 shy in front of you

156 **Interviewer:** you're welcome

**Appendix W: A Sample of Transcription, and Annotated transcript  
(British Participant, Study 2)**

Participant: 19

**Interviewer:** Thank you very much for your time.

**Respondent:** No problem

**Interviewer:** Thank you. You know about my topic, so I just wanted to know about the coping strategies that you may use in living with epilepsy?

**Interviewer:** May I ask how old are you?

**Respondent:** Thirty

**Interviewer:** Ok. When did you diagnosed with epilepsy?

**Respondent:** When I was 16

**Interviewer:** Ok, what type of epilepsy do you have?

**Respondent:** I've got complex partial seizure

**Interviewer:** Ok

**Interviewer:** Can you tell me how and in what way you cope with your epilepsy?

**Respondent:** Uhm, internet maybe, I would say, yeah

**Interviewer:** Ok how that internet could help you? Can you give me an example?

**Respondent:** When I get seizure I feel really strange afterword, and then I want to go and check what that seizure was for like, you know. For instance I could sometimes feel funny in my brain, which is like leaving my body before going to actual seizure. But after seizure I feel really curious to find out what's going on in my brain

**Interviewer:** yeah, I can understand you

**Respondent:** I'd prefer to search about it, rather than dwelling on it. Because the more you know about the problem, the much stronger you are

**Interviewer:** Ok, it's really good

**Interviewer:** Can you tell me what do you think is helpful in terms of coping?

**Respondent:** Uhm, the support maybe. Yeah, like the NHS is brilliant. It has been really helpful. I've been very happy with all specialists they all have been very nice to me, when I need them they are there for me. I can call them at any time of day. I remember when I was told that I've epilepsy; the nurse came to me and talked to me, she was trying to make me familiar with epilepsy.

What else, Uhm, free medication maybe; I don't need to pay for it. I also have free pass to all transportations, where I don't need to pay for them as well. I'm getting disability allowance, which is really helpful. So, when you think you just get on with it

**Interviewer:** That's really good, so you feel supported

**Respondent:** Exactly, yeah, with me these supports helps me to go through with it, otherwise, you just sit in the house all day long and you end up killing yourself (laugh). Because sometimes, yeah, your thoughts are really, really dark thoughts and you've had enough but you need to move and do something because otherwise you wouldn't be here by now.

**Interviewer:** Yes, exactly. Are you alright?

**Respondent:** No, I'm alright. Like I say you just get on with it. If you've got time to sit there and think, that's when you get down, that's why I always try to find about the seizures and stuff like that. Otherwise, I wouldn't be here because I get myself so down.

**Interviewer:** Yeash. Ok, some people with epilepsy might pass urine during their seizure, is this something you have experienced it ?

**Respondent:** Yeah, I wet myself during a fit

**Interviewer:** Oh, Ok then so you are familiar with this situation

**Respondent:** Yeah I know

**Interviewer:** So, then can you tell me how do you cope with it?

**Respondent:** Uhm, during the fit, I go without meaning to, yeah that has happened quite a lot. I remember when I was doing my diploma in childcare, it was eight years ago, I remember very well, I had one in the nursery and when I was waking up they were changing my trousers, they were soggy.

**Interviewer:** Ok then



**Respondent:** It happen quite often and obviously that is weird if it is in the public, everyone looks at me and says like, “Aren’t you a bit old for that?” And I am like, “I just had a bloody fit.” So, it’s weird.

**Interviewer:** Could you please tell me how do you find helpful in terms of coping with your incontinency?

**Respondent:** I’d say nothing. Uhm but my cousin has irritable bowel syndrome, and she wet herself most of time, she is unable to control it. My condition compare to her is not that much bad. Because I only wet myself during fit. You know, sometimes I’m trying to put it in a good perspective that at least I don’t have those pains or leaking for a whole day.

**Interviewer:** Ok, thank you very much for your time

**Respondent:** Your research must be fascinating

**Interviewer:** Thank you so much

-Annotated transcript

**Participant:** 19

**Nationality:** British

**Gender:** Female

**Age:** 30

**Age of diagnose:** 16

**Time since diagnosed:** 12 years

**Type of epilepsy:** Complex partial seizure

1 **Interviewer:** Thank you very much for your time.

2 **Respondent:** No problem

3 **Interviewer:** Thank you. You know about my topic,  
 4 so I just wanted to know about the coping strategies  
 5 that you may use in living with epilepsy?

6 **Interviewer:** May I ask how old are you?

7 **Respondent:** Thirty

8 **Interviewer:** Ok. When did you diagnosed with  
 9 epilepsy?

10 **Respondent:** When I was 16

11 **Interviewer:** Ok, what type of epilepsy do you have?

12 **Respondent:** I've got complex partial seizure

13 **Interviewer:** Ok

14 **Interviewer:** Can you tell me how and in what way  
 15 you cope with your epilepsy?

16 **Respondent:** Uhm, internet maybe, I would say, yeah

17 **Interviewer:** Ok how that internet could help you?  
 18 Can you give me an example?

19 **Respondent:** When I get seizure I feel really strange  
 20 afterword, and then I want to go and check what that  
 21 seizure was for like, you know. For instance I could  
 22 sometimes feel funny in my brain, which is like  
 23 leaving my body before going to actual seizure. But  
 24 after seizure I feel really curious to find out what's  
 25 going on in my brain

26 **Interviewer:** yeah, I can understand you

Age of person

Age of diagnosis

Type of Epilepsy

Information Seeking

Information Seeking

Sincere expression  
 Search for meaning

Sincere expression

Information  
Seeking

27 **Respondent:** I'd prefer to search about it, rather than  
28 dwelling on it. Because the more you know about the  
29 problem, the much stronger you are

Making preference  
Search for illness

30 **Interviewer:** Ok, it's really good

31 **Interviewer:** Can you tell me what do you thing is  
32 helpful in terms of coping?

Received  
Support

33 **Respondent:** Uhm, the support maybe. Yeah, like the  
34 NHS is brilliant. It has been really helpful. I've been  
35 very happy with all specialists they all have been very  
36 nice to me, when I need them they are there for me. I  
37 can call them at any time of day. I remember when I  
38 was told that I've epilepsy; the nurse came to me and  
39 talked to me, she was trying to make me familiar with  
40 epilepsy.

Receiving support  
NHS support  
Feeling satisfied

Received  
support

41 What else, Uhm, free medication maybe; I don't need  
42 to pay for it. I also have free pass to all  
43 transportations, where I don't need to pay for them as  
44 well. I'm getting disability allowance, which is really  
45 helpful. So, when you think you just get on with it

Knowing more about  
illness

Financial support  
Facilities  
available facilities  
try to accept illness

46 **Interviewer:** That's really good, so you feel  
47 supported

48 **Respondent:** Exactly, yeah, with me these supports  
49 helps me to go through with it, otherwise, you just sit  
50 in the house all day long and you end up killing  
51 yourself (laugh). Because sometimes, yeah, your  
52 thoughts are really, really dark thoughts and you've  
53 had enough but you need to move and do something  
54 because otherwise you wouldn't be here by now.

Being helped

Negative thoughts  
going through life

55 **Interviewer:** Yes, exactly. Are you alright?

Information  
Seeking

56 **Respondent:** No, I'm alright. Like I say you just get  
57 on with it. If you've got time to sit there and think,  
58 that's when you get down, that's why I always try to  
59 find about the seizures and stuff like that. Otherwise,  
60 I wouldn't be here because I get myself so down.

going thoughtless

Search for more  
information

61 **Interviewer:** Yeash. Ok, some people with epilepsy  
62 might pass urine during their seizure, is this  
63 something you have experienced it?

64 **Respondent:** Yeah, I wet myself during a fit

Passing urine

65 **Interviewer:** Oh, Ok then so you are familiar with  
66 this situation

67 **Respondent:** Yeah I know

68 **Interviewer:** So, then can you tell me how do you  
69 cope with it?

70 **Respondent:** Uhm, during the fit, I go without  
71 meaning to, yeah that has happened quite a lot. I  
72 remember when I was doing my diploma in childcare,  
73 it was eight years ago, I remember very well, I had  
74 one in the nursery and when I was waking up they  
75 were changing my trousers, they were soggy.

pass urine  
unconsciously

Experience of  
urinary pass

76 **Interviewer:** Ok then

77 **Respondent:** It happen quite often and obviously that  
78 is weird if it is in the public, everyone looks at me and  
79 says like, "Aren't you a bit old for that?" And I am  
80 like, "I just had a bloody fit." So, it's weird.

Not acceptable  
in public

81 **Interviewer:** Could you please tell me how do you  
82 find helpful in terms of coping with your  
83 incontinency?

*Downward  
Positive  
Comparison*

84 **Respondent:** I'd say nothing. Uhm but my cousin has  
85 irritable bowel syndrome, and she wet herself most of  
86 time, she is unable to control it. My condition  
87 compare to her is not that much bad. Because I only  
88 wet myself during fit. You know, sometimes I'm  
89 trying to put it in a good perspective that at least I  
90 don't have those pains or leaking for a whole day.

91 **Interviewer:** Ok, thank you very much for your time

92 **Respondent:** Your research must be fascinating

93 **Interviewer:** thank you so much

*No practical  
activities  
Feeling comparison*

*Accepting the  
condition*

*Feeling better  
in comparison to  
cousin  
Feeling positive*

**Appendix X: A Sample of Transcription, and Annotated transcript**  
**(Iranian Participant, Study 2)**

Participant: 3

**Interviewer:** Thank you very much for you time

**Respondent:** You're welcome

**Interviewer:** Do mind if I ask you how old are you?

**Respondent:** I'm 35.

**Interviewer:** Ok, when did you diagnose with epilepsy?

**Respondent:** when I was 12

**Interviewer:** Ok. What type of epilepsy do you have?

**Respondent:** it's called Temporal lobe epilepsy

**Interviewer:** Ok, it has been long time for you living with epilepsy, right?

**Respondent:** Yeah, it is long time

**Interviewer:** Ok, can you tell me how do you cope with your epilepsy?

**Respondent:** I am not sure really...! How to say...do you mean how did I manage to live with it?

Interviewer: yes exactly

Respondent: Ok, Uhm, it has been quite a long time living with epilepsy, it has not been easy for me to live with it because I really couldn't accept the fact that I am ill... and being treated like an ill person!

**Respondent:** However I have to accept that life is continues and we should live in this world

**Interviewer:** yeah I know

**Respondent:** Uhm

**Interviewer:** Are you living alone?

**Respondent:** No I am living with my husband and my little son, my husband still couldn't accept that I am ill, but he is showing me his respect anyway!

**Interviewer:** is he supportive?

**Respondent:** Sometimes he is.. But the thing is, he is working full time and does not have specific time for me so most of the time I am with my son... and I really enjoy spending time with him.

**Respondent:** Sorry, what was your question again?

**Interviewer:** I was trying to know, how do you cope with epilepsy?

**Interviewer:** Or... how do you manage your epilepsy?

**Respondent:** Yeah, in terms of managing my illness, my parents have been very helpful specially my Mum. I have received the best support ever from my Mum;

**Interviewer:** Oh really: what has she done for you?

**Respondent:** She is amazing. She has been always helpful she looks after me very well. She understands me and to be honest with you, I'm lucky to have her in my life. With her, I've never felt alone, even though I do have a married life but I do cope well as I've received amazing support from her. She buys me everything I need (laughing). Even with my medication, I do sometimes forget to take them, but Mum always reminds me to take them just in case of getting seizure. She is fantastic. I'm so glad to have her.

**Interviewer:** that's really good that you have your Mum beside you.

**Respondent:** Yeah, it's fantastic feeling to have someone understanding you, when I need shopping; I just call her and say... Mum do you want to go out? And she is like yeah lets go and I am saying... yay its shopping time (laughing).

**Interviewer:** Apart from your Mum, are you receiving any other support?

**Respondent:** Uhm, maybe my son... After seizure, he comes to me and hugs me and I feel like really relieved! You know... the children are amazing really, they understand more than we think!

**Interviewer:** Yes I can understand you. Can you tell me what do you think is helpful in terms of coping?

**Respondent:** I can only say the support from family; otherwise I wouldn't be able to survive really. Yeah

**Interviewer:** Ok that's fine. Are you passing urine during your seizure?

**Respondent:** Do you mean I wet myself?



**Interviewer:** Yeah, I heard that some people with epilepsy pass urine during the seizure. Is this something that you have gone through with it?

**Respondent:** Yes it happens to me sometimes, but it depends on my seizure activity

**Interviewer:** Can you explain me more?

**Respondent:** When I am getting tonic-clonic seizures, I might pass urine but sometimes I only stare to some point and seizure attacks me, so in that case I do not wet myself!

**Interviewer:** OK, I got it. Can you tell me how do you cope with urine pass, in this case?

**Respondent:** Uhm, it's difficult to answer but, I strongly believe in God and I am sure he has always been helpful to me in this respect.

**Interviewer:** can you explain more that how do you feel like God can help you in terms of passing urine?

**Respondent:** Uhm, it's kind of feeling really, difficult to put into word. I do believe that God is my protector; I feel more confident and believe in that I won't pass urine! If I pray to God, It might be looks silly, but this is me, this is who I am. I used to go to Holly shrine

**Interviewer:** Oh really which one

**Respondent:** Yeah, to Imam Reza Shrine. Yeah I think this is really personal feeling no one can perceive the way you perceive your life. Can you understand what I mean?

**Interviewer:** Yeah go head please

**Respondent:** Yeah, when I was younger I used to go there with my Dad, but since I got epilepsy it just turning to be a relaxing point for me to be there and release my emotions there. Whenever I go there, I do really cry and release my emotions and feel much better to be honest.

My Mum also gave me written prayers which I'm always taking them with me, it just gives me confidence that nothing going to happen. Even if I want to go party, I strongly pray to God to not wet myself in there. Because I hate the way people treating me; so the belief really empowers me.

**Interviewer:** Ok I see, what you mean

**Interviewer:** do you want to add something more? If you like

**Respondent:** no I think I'm fine

**Interviewer:** OK, thank you very much for taking part

**Respondent:** no problem at all.

-Annotated transcript

**Participant:** 3

**Gender:** Female

**Nationality:** Iranian

**Age:** 35

**Epilepsy type:** Temporal lobe epilepsy

**Age of diagnose:** 12 years old

**Time since diagnosed:** 23 years

1 **Interviewer:** Thank you very much for you  
2 time

3 **Respondent:** You're welcome

4 **Interviewer:** Do mind if I ask you how old are  
5 you?

6 **Respondent:** I'm 35.

7 **Interviewer:** Ok, when did you diagnose with  
8 epilepsy?

9 **Respondent:** when I was 12

*Age of diagnosis*

10 **Interviewer:** Ok. What type of epilepsy do  
11 you have?

12 **Respondent:** it's called Temporal lobe  
13 epilepsy

*Epilepsy type*

14 **Interviewer:** Ok, it has been long time for you  
15 living with epilepsy, right?

16 **Respondent:** Yeah, it is long time

17 **Interviewer:** Ok, can you tell me how do you  
18 cope with your epilepsy?

19 **Respondent:** I am not sure really...! How to  
20 say...do you mean how did I manage to live  
21 with it?

22 **Interviewer:** yes exactly

23 **Respondent:** Ok, Uhm, it has been quite a long  
24 time living with epilepsy, it has not been easy  
25 for me to live with it because I really couldn't  
26 accept the fact that I am ill... and being treated  
27 like an ill person!

*Accepting of living  
with Epilepsy later  
in life  
Difficulties of  
living with Epilepsy*

28 **Respondent:** However I have to accept that life  
29 is continues and we should live in this world

*Acceptance*

30 **Interviewer:** yeah I know

31 **Respondent:** Uhm

32 **Interviewer:** Are you living alone?

33 **Respondent:** No I am living with my husband  
34 and my little son, my husband still couldn't  
35 accept that I am ill, but he is showing me his  
36 respect anyway!

*Not acceptable for others*

37 **Interviewer:** is he supportive?

38 **Respondent:** Sometimes he is.. But the thing is,  
39 he is working full time and does not have  
40 specific time for me so most of the time I am  
41 with my son... and I really enjoy spending time  
42 with him.

*Feeling good with son*

43 **Respondent:** Sorry, what was your question  
44 again?

45 **Interviewer:** I was trying to know, how do you  
46 cope with epilepsy?

47 **Interviewer:** Or... how do you manage your  
48 epilepsy?

*Social support*

49 **Respondent:** Yeah, in terms of managing my  
50 illness, my parents have been very helpful  
51 specially my Mum. I have received the best  
52 support ever from my Mum;

*Supportive family  
Feeling happy with mother*

53 **Interviewer:** Oh really: what has she done for  
54 you?

Social support

55 **Respondent:** She is amazing. She has been  
56 always helpful she looks after me very well. She  
57 understands me and to be honest with you, I'm  
58 lucky to have her in my life. With her, I've  
59 never felt alone, even though I do have a  
60 married life but I do cope well as I've received  
61 amazing support from her. She buys me  
62 everything I need (laughing). Even with my  
63 medication, I do sometimes forget to take them,  
64 but Mum always reminds me to take them just  
65 in case of getting seizure. She is fantastic. I'm  
66 so glad to have her.

Good impression for  
mother

Feeling lucky

Social support

67 **Interviewer:** that's really good that you have  
68 your Mum beside you.

Feeling satisfied  
with support  
from mother

Being helpful  
in terms of  
taking medication

Social support

69 **Respondent:** Yeah, it's fantastic feeling to have  
70 someone understanding you, when I need  
71 shopping; I just call her and say... Mum do you  
72 want to go out? And she is like yeah lets go and  
73 I am saying... yay its shopping time (laughing).

Feeling of being  
understood

Feeling good

74 **Interviewer:** Apart from your Mum, are you  
75 receiving any other support?

Emotional  
expression

76 **Respondent:** Uhm, maybe my son... After  
77 seizure, he comes to me and hugs me and I feel  
78 like really relieved! You know... the children  
79 are amazing really, they understand more than  
80 we think!

Emotional feeling  
from son

81 **Interviewer:** Yes I can understand you. Can  
82 you tell me what do you think is helpful in  
83 terms of coping?

84 **Respondent:** I can only say the support from  
85 family; otherwise I wouldn't be able to survive  
86 really. Yeah

The importance of  
Family support

87 **Interviewer:** Ok that's fine. Are you passing  
88 urine during your seizure?

89 **Respondent:** Do you mean I wet myself?

90 **Interviewer:** Yeah, I heard that some people  
91 with epilepsy pass urine during the seizure. Is  
92 this something that you have gone through with  
93 it?

94 **Respondent:** Yes it happens to me sometimes,  
95 but it depends on my seizure activity

changing the situation

96 **Interviewer:** Can you explain me more?

97 **Respondent:** When I am getting tonic-clonic  
98 seizures, I might pass urine but sometimes I  
99 only stare to some point and seizure attacks me,  
100 so in that case I do not wet myself!

Urinary pass in  
severe seizure attack

Not passing urine  
in mild attack

101 **Interviewer:** OK, I got it. Can you tell me how  
102 do you cope with urine pass, in this case?

103 **Respondent:** Uhm, it's difficult to answer but, I  
104 strongly believe in God and I am sure he has  
105 always been helpful to me in this respect.

Religious beliefs  
Feeling assured

106 **Interviewer:** can you explain more that how do  
107 you feel like God can help you in terms of  
108 passing urine?

109 **Respondent:** Uhm, it's kind of feeling really,  
110 difficult to put into word. I do believe that God  
111 is my protector; I feel more confident and  
112 believe in that I won't pass urine! If I pray to

hard to say about  
inner sense

Feeling protected  
Feeling confident

Religious  
Coping

Religious  
Coping

Religious coping

113 God, It might be looks silly, but this is me, this  
114 is who I am. I used to go to Holly shrine

Believe in self  
Religious activity

115 **Interviewer:** Oh really which one

116 **Respondent:** Yeah, to Imam Reza Shrine. Yeah  
117 I think this is really personal feeling no one can  
118 perceive the way you perceive your life. Can  
119 you understand what I mean?

Different perception

120 **Interviewer:** Yeah go head please

Religious coping

121 **Respondent:** Yeah, when I was younger I used  
122 to go there with my Dad, but since I got  
123 epilepsy it just turning to be a relaxing point for  
124 me to be there and release my emotions there.

Past experience

Emotional expression

Feeling relaxed

Emotional coping

125 Whenever I go there, I do really cry and release  
126 my emotions and feel much better to be honest.

Emotional being emotional

Religious coping

127 My Mum also gave me written prayers which  
128 I'm always taking them with me, it just gives  
129 me confidence that nothing going to happen.  
130 Even if I want to go party, I strongly pray to  
131 God to not wet myself in there. Because I hate  
132 the way people treating me; so the belief really  
133 empowers me.

Believe in religion

Feeling confident

managing the  
crisis pass

Strong belief

134 **Interviewer:** Ok I see, what you mean

135 **Interviewer:** do you want to add something  
136 more? If you like

137 **Respondent:** no I think I'm fine

138 **Interviewer:** OK, thank you very much for  
139 taking part

140 **Respondent:** no problem at all.