Quality of Life and Stigma in People with Epilepsy:
&
Knowledge and Stigma Concerning People with Epilepsy in the UK & Kurdistan, Northern Iraq

A Thesis Submitted for the Degree of
Doctor of Philosophy

By

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Declaration

I, Nashmel Sargalo, confirm that the research presented in this thesis is my own work, where references have been made to other sources, this has been cited accordingly.

Nashmel Sargalo

Dedication

To my loved ones.

Abstract

This project aimed to explore the lives of people with epilepsy living in the UK and Kurdistan, Northern Iraq, using qualitative and quantitative methods with a particular focus on stigma and quality of life. This study further explored others' perceptions concerning those with epilepsy, particularly in regards to knowledge and stigma about epilepsy. Participants were all over the age of 18. The UK sample was recruited from personal contacts and Epilepsy Action conferences. The Kurdistan participants were recruited from Neurology clinics and personal contacts. Data collection consisted of snowball and convenience sampling. The first study was a qualitative investigation looking at people with epilepsy, 10 participants from the UK and 10 participants from Kurdistan were interviewed using semi-structured interviews. The interview schedule was exploratory and non-intrusive. The transcripts were analysed using thematic analysis. From the analysis five main themes were uncovered; they were (1) The Experience of Seizures; (2) Impact of Living with Epilepsy; (3) Adjustment; (4) Coping and; (5) Stigma, each with two sub-themes.

The second study was a quantitative study of people with epilepsy which looked at knowledge of epilepsy, seizure severity, perceived illness seriousness, perceived stigma, depression and quality of life. The total number of participants that took part in the second study was 84 participants in the UK group and 88 in the Kurdistan group. Using Hierarchical Multiple Regression, the results showed that depression and stigma, mediated by depression, are main predictors of quality of life amongst people with epilepsy. The third study investigated people without epilepsy which looked at knowledge of epilepsy and stigma regarding people with the condition. There were 116 participants in the UK group and 200 from the Kurdistan group. Using ANCOVA, Multivariate General Linear Model and Linear Regression, the results showed that the UK participants had significantly better knowledge of epilepsy compared to the Kurdistan group; however, although stigma was higher among the Kurdish group, a significant result was not observed.

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Contents

List of Tables

Chapter 1: Epilepsy

The stigma associated with an embarrassing or shameful illness can impact on the quality of life of a person. The stigma associated with conditions such as epilepsy has been documented in literature (Jones et al., 1984; Doughty, Baker, Jacoby & Lavaud, 2003; Jacoby, & Austin, 2007; World Health Organisation, WHO, 2010). However, less is understood about the effects of stigma in less developed countries (WHO, 2010). The World Health Organisation (2010) has reported that, out of all neurological conditions, epilepsy is the most common and is not bound by age, social standing or race. This thesis explores the effects of an epilepsy diagnosis on people from two very different areas of the world. This research was inclusive of people with epilepsy, and a further exploration of people without epilepsy, in the UK, a developed country and Kurdistan in Northern Iraq, situated in a developing region of the world.

1.1. What is Epilepsy?

Epilepsy is one of the most debilitating neurological conditions and is quite unique in its symptoms and types compared to other forms of neurological disorders. Conditions, such as cerebral palsy, which is present from birth (Rosenbaum et al., 2007; Bax et al., 2005); and Alzheimer's (Rossor, Iversen, Reynolds, Mountjoy, & Roth, 1984; Dubois, 2010; Ballard et al., 2011) and Parkinson disease (de Lau, & Breteler, 2006) are mainly associated with old age.

A simple definition of epilepsy is an ongoing tendency to have regular epileptic seizures, and is diagnosed when a person experiences more than one episode (Hopkins & Appleton, 1996). The International League Against Epilepsy (ILAE) is an organisation that considers itself to be accessible to anyone for complete information on epilepsy (ILAE Website, 2014). According to ILAE, epilepsy is defined as a brain disorder which leads a person with the condition to have epileptic seizures (Fisher et al, 2014). The ILAE (2005) provisionally defined epilepsy as ‘‘a disorder of the brain characterised by an enduring predisposition to generate epileptic seizures’’ (Fisher et al., 2014, p.475). The current definition set out by the

ILAE is of a person experiencing a minimum of two motiveless seizures in over 24 hours, or one epileptic seizure and the likelihood of other seizures occurring due to brain damage, caused by stroke or infection of the brain (ILAE, 2014). A person can also have a diagnosis of epilepsy syndrome (ILAE, 2014). A diagnosis of epilepsy syndrome is given if evidence exists for such a diagnosis, for example, the spikes from an electroencephalogram (EEG) show that a seizure can be detected during sleep, but the individual does not always show the physical signs of a seizure. This is more consistent with Benign Rolandic Epilepsy in Children (BREC) and Benign Epilepsy with Centro-Temporal Spikes (BECTS) in children (Pavlou, Gkampeta, & Athanasiadou- Piperopoulou, 2012). According to the ILAE, if a person is seizure free for over ten years and is medication free for the last five years, the condition can be defined as ‘resolved’, however, this is not to be mistaken with cured epilepsy or being in remission, which may be associated with a more permanent state of the condition (ILAE, 2014). When referring to epilepsy in this thesis, the definition as set out by ILAE will be used for the purposes of this research.

The brain’s normal activity is that it continuously generates electrical impulses in a systematic pattern (Chadwick & Usiskin, 1992). These impulses travel along the network of nerve cells called neurons. Neurons transmit information in the brain and throughout the body via chemical messengers called neurotransmitters. Seizures happen as a result of an uncontrolled and sudden surge of electrical activity. For an epileptic seizure to occur thousands of nerve cells have to behave abnormally or an excessive burst of electrical impulses in the brain and not simply a single or handful of cells showing unusual behaviour (Chadwick & Usiskin, 1992; Tamber & Mountz, 2012).

There are two main types of classifications of epilepsy, depending on how much of the brain is involved during a seizure. There are (1) Generalised and (2) Focal (Partial) Seizures (Chadwick & Usiskin, 1992). Generalised Seizures involve most or the whole of the brain and focal (partial) involves a small area of the brain. There are six types of generalised seizures. The first is (1a) Absences in which the person loses awareness of their environment and tends to stare into space, this is more frequent in children but can also happen to adults. (1b) Myoclonic Seizures are the type where the person is affected by their arms, legs or upper body jerking as if electrocuted, and can happen with any other type of generalised seizures (Chadwick & Usiskin, 1992). The (1c) Clonic Seizures are similar to the Myoclonic symptoms but last longer and the person may lose consciousness. The fourth type of Generalised Seizure is (1d) Atonic Seizures which is characterised when all the muscles of the body are relaxed and the person falls to the ground. The fifth type is the (1e) Tonic which is the opposite of the Atonic and this is where all the muscles become stiff which may cause an imbalance. The final type is the (1f) Tonic-Clonic Seizure which is widely recognised and is when the body first becomes stiff, the limbs will start twitching and some people may lose bladder control. This is where the person has lost consciousness and the seizure can last for a few minutes or longer (Chadwick & Usiskin, 1992).

There are two types of Partial Seizures. The first is the (2a) Simple Partial Seizure, this is when the person is conscious and the seizure is characterised by a feeling of 'déjà vu', a strange smell or taste and twitching in some parts of the body (Chadwick & Usiskin, 1992). The second is (2b) Complex Partial Seizure in which the person loses their awareness or memory of the seizure and is unable to respond to those around them. This type is characterised by behaviours such as fiddling with objects, smacking lips, chewing and moving unusually (Chadwick & Usiskin, 1992).

A rare type of seizure named after the British Neurologist, Hughling Jackson, is called the Jacksonian Seizure (Chadwick & Usiskin, 1992). Jacksonian seizures are characterised by the seizure affecting one part of the body and spreading to the rest. An example of this is a jerking beginning in the left thumb, then affecting the whole hand, then the arm and gradually to that half of the body, this then leads to a generalised seizure (Chadwick & Usiskin, 1992).

A seizure only becomes an emergency if it lasts longer than 30 minutes, in which case the person is in Status Epilepticus (Chadwick & Usiskin, 1992). Status Epilepticus is also characterised by seizures occurring one after the other without much time elapsing between them. Another definition is ''generalised, convulsive status epilepticus referring to a condition in which there is a failure of the 'normal' factors that serve to terminate a typical GTCS'' (Generalised Tonic-Clonic Seizure) according to Lowestein, Bleck, and Macdonald (1999, p.121) and suggest that this is the definition researchers should use. Epilepsy is not to be confused with pseudo-seizures which are a psychological reaction to traumatic experiences (Harden, 1997).

1.2. Incidence

Approximately 10 million people are living with neurological conditions in the UK (Leyshon, 2005) and epilepsy affects 1 in 103 people, however, this figure is higher for those with learning disabilities, which is 1 in 5 (National Institute for Health and Care Excellence, NICE, 2015). Around 10% of the general population are likely to experience a single seizure in their lifetime; however, this does not meet the requirements for an epilepsy diagnosis (ILAE, 2014; WHO, 2015). It has been reported that childhood epilepsy rates in developed countries have fallen in the last three decades, however; there has been an increase in the rates of elderly epilepsy (Duncan, Sander, Sisodiya, & Walker, 2006).

The incidence rate in the UK is around 50 to 80 in every 100,000 (less than one in every 1,000 or .5 to .8 in every 1,000) (Kelso & Cock, 2004). In a systematic review of high, middle and low income countries, it was reported that, compared to high income, the prevalence of epilepsy is twice as high in the middle to low income countries (Ngugi et al., 2011). However, a door to door household survey in Hawler, Iraqi Kurdistan, showed that the prevalence of epilepsy is 9.7 in every 1,000 (Khidr & Sheikh-Bzeni, 2011). That is 10 times higher compared to the reported prevalence in the UK. This is also considerably higher compared to China, which is 7 in every 1,000 (Wang et al., 2003). Additionally, in Senegal, a low income country, the prevalence of epilepsy occurrence is even higher at 14 in every 1000 (Ndoye et al., 2005). These figures show that those living in high income countries, which is more associated with developed societies, have fewer epilepsy incidence compared to low to middle income or developing countries. The WHO has suggested that approximately 50 million people are diagnosed with epilepsy worldwide and the majority, 85%, live in the developing countries (WHO, 2010).

1.3. Causes of Epilepsy

Some causes of epilepsy are unknown and appear to be without a reason, whilst others can sometimes occur as a consequence of an accident or illnesses such as meningitis, in which case it is linked to a particular event (Kelso & Cock, 2004; Duncan et al., 2006; Newton & Garcia, 2012). One of the indiscriminate causes of epilepsy across all societies is a head injury (Newton & Garcia, 2012). Causes associated with developing countries are viral infections, poor perinatal care, and lack of oxygen to the foetus during labour and childbirth, and poorly managed febrile seizures (Newton & Garcia, 2012). It is a possibility that better facilities are more widely available to those in the UK and this may explain the declining rates of childhood epilepsy in the developed countries (Duncan et al., 2006). The causes of epilepsy that are reported to be similar in both the developed and developing countries are genetic associations and gender. It is reported that higher rates of epilepsy are more prevalent in males compared to females across all societies (Newton & Garcia, 2012). Low socioeconomic status and poor nutrition have further been associated with epilepsy, this is across developing and developed regions in the world (Morgan, Ahmed, & Kerr, 2000; Heaney et al., 2002; Alanis-Guevara et al., 2005; Newton & Garcia, 2012). A recent study has linked epilepsy prevalence to social causations associated with deprived societies, such as income and education (Pickrell et al., 2015) which are similar to that in developing regions (Newton & Garcia, 2012). This is in contrast to claims that epilepsy is a non-discriminate condition (WHO, 2010). Furthermore, it is suggested that malnutrition plays a great part in epilepsy and that it is important to tackle this issue in the developing countries to ensure the incidence of epilepsy are kept under control (Crepin, Godet, Chassain, Preux, & Desport, 2009).

The World Health Organisation (Beghi, 2004; WHO, 2010) has suggested three main classifications for the causes of epilepsy. The first one is Remote Symptomatic which is seizures occurring spontaneously due to brain malfunction, such as stroke, head trauma or intracranial infection (WHO, 2010). The second classification is Idiopathic which is understood to have a genetic link, although further research is necessary for confirmation, and the third classification is Cryptogenic which is the category where the cause is unknown (WHO, 2010). The WHO further highlights that epilepsy may have a social cause, which may come under the Cryptogenic category, and that the onset of epilepsy is sometimes caused by stress (WHO, 2010). This suggestion should not be too quickly dismissed as it has been reported that the majority of those living with epilepsy come from the developing countries (WHO, 2010).

1.4. Diagnosis

Epilepsy can be a lifelong condition, but a person can also be seizure free for a long time and sometimes even grow out of seizures (Benign Rolandic Epilepsy), especially if it is diagnosed in early childhood (Sillanpää & Schmidt, 2006), and is not associated with other neurological conditions, such as cerebral palsy. Furthermore, epilepsy is different in that, depending on the type of seizure a person experiences, it can be a private condition (Jacoby, Gorry, Gamble, & Baker, 2004).

The diagnosis and occurrence of neurological conditions vary between the different types of disorders.. Some neurological conditions, such as cerebral palsy are lifelong, whilst others are known to be degenerative and worsen over time, such as motor neuron disease and multiple sclerosis (Bax et al., 2005; Rosenbaum et al., 2007; The Neurological Alliance, 2013). These neurological conditions (motor neuron disease and multiple sclerosis) are mostly associated with adulthood (The Neurological Alliance, 2013). Epilepsy is different to other forms of neurological conditions in that it can be diagnosed at any stage of a person’s life and diagnosis can sometimes be without obvious causes (Kelso & Cock, 2004; Duncan et al., 2006; WHO, 2010).

When it comes to diagnosing epilepsy, identifying the symptoms can be difficult as the person experiencing the seizures, in some cases, may be unconscious or unaware of the episodes, especially if they are only seizing nocturnally (Husain & Sinha, 2011). In the majority of cases, it helps the medical professional to have a family member or a friend who has witnessed the seizures to be able to explain the nature of the episodes (Chadwick & Usiskin, 1992; Kaski & Cockerell, 2015). Before any diagnosis is made, a full medical history as well as blood tests, Magnetic Resonance

Imaging (MRI) which shows the brain and its structure, to check for possible presence and causes of epilepsy (Binder et al., 2002), and electroencephalography (EEG) which records brain activity (Kannathal, Choo, Acharya, & Sadasivan, 2005), are completed. Although, it is important to note that even if an EEG does not pick up abnormal activity in the brain, the person can still have an epilepsy condition (Smith, 2005). Due to its many types of symptoms and investigations required, epilepsy can take anything from weeks to months to diagnose in the UK (Kaski & Cockerell, 2015).

An epilepsy diagnosis can be restrictive, and a UK study has highlighted the biggest impacts of an epilepsy diagnosis amongst all participants were work and education restrictions (Moran et al., 2004).

1.5. Treatment

In developed countries, the majority (60-70%) of those with epilepsy have their seizures controlled with antiepileptic drugs (AED) (Schmidt, 2009); however, there are other options for those unable to control their symptoms with medication. The possibility of brain surgery is available to adults where the decision is taken by the surgeon to either remove the damaged or affected area of the brain, or separate the two cerebral hemispheres to limit the seizure activity affecting the whole brain (Chadwick & Usiskin, 1992; Tamber & Mountz, 2012). Another treatment may be the Vagus Nerve Stimulation (VNS) in which impulses are regulated to avoid a sudden surge which causes a seizure (Kelso & Cock, 2004; Vonck, Raedt, & Boon, 2010; Aalbers et al., 2011; Tamber & Mountz, 2012). Deep Brain Stimulation (DBS) is a last resort treatment if medication and brain surgery do not ease symptoms (Labar 2004; Tamber & Mountz, 2012). Deep Brain Stimulation is where the brain is stimulated by using electrodes to relieve a person of unstoppable seizures (Okun et al., 2004). Another available treatment option is based on dieting alone. The Ketogenic Diet is a high fat diet and can only be undertaken under the supervision of a dietician (Kim, & Rho, 2008; Greener, 2014). This plan is only available for children in the UK; however, a pilot study is underway for adults, in cases where medication does not help to relieve the symptoms of epilepsy.

A person with epilepsy may become aware that certain factors could contribute to the onset of a seizure and act as a trigger, such as lack of sleep, high temperature, menstruation, stress and flashing lights (Sperling, Schilling, Glosser, Tracy, & Asadi-Pooya, 2008). Those with epilepsy who are aware of their triggers could protect themselves from recurring seizures by maintaining a healthy lifestyle and avoiding some of the triggers associated with the onset of the symptoms. Self-reported online data collected directly from people with epilepsy, mainly from the USA, showed that menstruation and lack of or disturbed sleep was rated as the highest triggers for people with epilepsy (Le, Shafer, Bartfeld, & Fisher, 2011). However, awareness of seizure triggers has been reported to cause more anxiety compared to those who are unaware of their triggers (Sperling et al., 2008).

In searching for psychological treatments of epilepsy, a study found that relaxation therapy did not make any difference to seizure frequency (Ramaratnam, Baker, & Goldstein, 2008). However, Cognitive Behavioural Therapy (CBT) did make an improvement to the associated symptoms of epilepsy, such as depression, and had a positive impact on quality of life (Ramaratnam et al., 2008). Yoga has also been shown to be an effective tool for reducing seizure frequency and duration (Ramaratnam, 2001, Lundgren, Dahl, Yardi, & Melin, 2008). In addition, Acceptance and Committal Therapy (ACT) which is accepting the condition that a person has and committing to a positive behaviour change (Hayes, 2004) teamed with yoga significantly impacts on the improvement of quality of life of people with epilepsy (Lundgre et al., 2008).

It is suggested that newly diagnosed people with epilepsy can fall into three categories or groups in regards to the longevity of their condition and symptoms (Kwan & Sander, 2004). The first group is said to have an excellent prognosis as about 20-30% can have long term seizure freedom with or without treatment, although with treatment and medication remission or ‘resolution’ (ILAE, 2014) may occur earlier (Kwan & Sander, 2004). The second group can have seizure freedom with treatment, and this can affect around 20-30% of people with epilepsy (Kwan & Sander, 2004). The third group tends to have the worst prognosis as even with treatment it is suggested that around 30-40% will continue experiencing seizures

(Kwan & Sander, 2004). A UK study has shown that around half of those taking AEDs continued to experience seizures (Moran et al., 2004).

The WHO proposes that 90% of epilepsy seizures are insufficiently controlled in the developing countries, and Kurdistan is situated in a developing region (WHO, 2010). This may be due to the suggestion that in the developing countries between 70-94% of people with epilepsy do not receive treatment for their symptoms (Sridharan, 2002). A possible explanation for this could be that people in the developing countries may feel that medication does not have any connection to lower seizure occurrences and choose not to get treated. Another probability may be associated to the lack of knowledge about the condition and symptoms or due to the negative stereotypes of epilepsy (WHO, 2010). Consequently, people with epilepsy may not acknowledge their diagnosis fully and furthermore be in denial about their condition. The reason for insufficient seizure control in the developing countries could also be linked to that in the developed countries anti-epileptic drugs (AED) are prescribed if a person experiences seizures in the last 2-5 years, however, in the developing countries medications are prescribed if seizures have occurred only within a year (Mbuba & Newton, 2009).

According to the WHO (2011), it is estimated that in the developed countries around 50% of people with chronic conditions adhere to medication (WHO, 2003; Brown & Bussell, 2011), this figure is even lower for developing regions (Mbuba & Newton, 2009), such as the Middle-East. Not adhering to a correct medication regime by those with epilepsy, may have some association with reports of high percentages of uncontrolled symptoms of the condition in the Middle-East (WHO, 2003; 2010). A study in America has shown that although people with epilepsy have a high efficacy to adhere to a correct medication timetable to control the symptoms of the condition, the same conviction is not applied to a healthy lifestyle (Kobau & DiIorio, 2003), which may have a negative impact on the symptoms associated with epilepsy.

1.6. Psychosocial Effects of Epilepsy

Epilepsy is a chronic condition and those diagnosed with it have been reported to show characteristics associated with learnt helplessness (further discussed in chapter two) (Rosenbaum, 1984; Amir, Roziner, Knoll, & Neufeld, 1999). Lack of knowledge about epilepsy has also been related to people with the condition which may lead to discrimination and stigma by others in society (Brigo et al.,2015).

Knowledge of epilepsy as a neurological condition has advanced greatly in the last few decades in the developed countries (Kelso & Cock, 2004), and the psychological effects, such as anxiety and depression, of this chronic condition are also reported widely (Johnson, Jones, Seidenberg, & Hermann, 2004; Raggi, Leonardi, D'Amico, Villani, & Quintas, 2015). Additional psychosocial consequences of epilepsy, for those with the condition, are emotional difficulties and poorer reported quality of life (Raggi et al., 2015). Further suggestions are made in relation to anxiety, which has been found to be a significant predictor of quality of life (Jacoby, Snape, Lane, & Baker, 2015). Epilepsy has also been associated with sleep disturbances due to the condition itself and the medication required for the control of the symptoms (Bazil, 2003; Jacoby et al., 2015).

Depression has been associated with people with epilepsy (Drinovac et al., 2015; Micoulaud-Franchi et al., 2015), and it is a significant issue for people with the condition (Kanner, 2006; Mehndiratta & Sajatovic, 2013). Depression is reported to be a response mechanism to difficulties in life, epilepsy is that obstacle that could lead to depression and requires management (Can, 2011). Behaviour theories of depression state that depression is a learned response to the absence of positive reinforcement (Lewinsohn, 1974). The *Cognitive Theory of Depression*, on the other hand, postulates that depression is a combination of three factors; the first is the individual’s own negative thoughts about themselves, the second is negative thoughts about the environment and finally negative thoughts about future prospects (Beck, 2002). Individual’s thoughts are said to be based on early learning and the society in which they live in. According to this model, negative thoughts can be changed by thinking about things in a positive way (Clark & Beck, 2010). This is the theory behind the *Cognitive Behavioural Therapy* (CBT) used in treating depression generally, as well as in epilepsy (Clark & Beck, 2010).

Depression negatively influences quality of life and increases suicide rates in people with epilepsy (Kanner, 2006; Kondziella & Asztely, 2009). However, recognising the symptoms of depression are not always so clear cut in a clinical setting (Drinovac et al., 2015). A model, using visual and verbal scales, has been developed to detect depressive symptoms in medical environments to aid physicians recognise depression in people with epilepsy (Drinovac et al., 2015). Depression is not only an issue for those with epilepsy but it is also a factor that affects carers of people with the condition (Hoppe & Elger, 2011).

As discussed above, high levels of anxiety and depression have been associated with people with epilepsy; furthermore, low self-esteem is also reported to be linked to those the condition (De Boer, Mula, & Sander, 2008). It is further reported that stigma can have a negative impact on self-esteem, however, it has been shown that support groups can help raise self-esteem in people with epilepsy (Sawangchareon, Pranboon, Tiamkao, & Sawanyawisuth, 2013). The theory of social comparison explains that humans are compelled to compare themselves socially, almost like a competition (Festinger, 1954). This evaluation between the outside world and an individual is unidirectional, making comparisons based on abilities (Festinger, 1954). This comparison can be upward, where a comparison is made with people better off than the individual or downward comparison where people worse off are compared (Festinger, 1954). In a study of people with intellectual disability, it has been reported that better self-esteem positively correlates with social comparison. Furthermore, social comparison and self-esteem both negatively correlate with depression (Dagnan & Sandhu, 1999). Dagnan and Sandhu (1999) conclude that the relationship between social comparison, self-esteem and depression are the same between intellectually disabled and able people .

1.7. Epilepsy in Context

In research to understand certain behaviours, it is crucial to understand the differences between the rules of different societies and cultures. As this research concentrates on two very different societies, the UK and Kurdistan, an understanding of what the characteristics of these cultures are play an important role in the behaviour of its members. Culture is the indoctrination of the mind shared by a group of people in any given society (Hofstede, 1984). One of the dimensions of culture is individualism and collectivism which looks at the level of individuality present among members of a given society (Hofstede, Hofstede, & Minkov, 1991). Societies can belong to either an individualistic or collectivist culture (Hofstede, 1980). Individualistic cultures are more common in Western Societies such as Europe and North America and collectivist cultures are found in the Middle-East, Africa and Asia (Triandis, Brislin, & Hui, 1988; Hofstede, 2001). Members of individualistic societies are expected to look after themselves and their close family and the ties between the individuals are ‘loose’ (Hofstede et al., 1991). Whilst in collectivist societies, the individual’s identity is part of a larger set up within the extended family and community (Hofstede, 2001). Furthermore, individualistic societies are more associated with wealthy countries, in contrast to collectivist cultures which are more prevalent in poorer countries, and wealth is known to precede individualism (Hofstede, 2001).

It is suggested that the members of a collectivist culture learn information through social interaction while those from individualistic cultures are informed by the media (Hofstede et al., 1991). It is further noted that there are fewer human rights in collectivist societies and they have less press freedom compared to individualistic cultures (Hofstede, 2001). According to the classification of individualistic and collectivist cultures (Hofstede, 2001), it appears that the UK is considered as an individualistic society whilst those living in Kurdistan, North of Iraq, are part of the societies in the collectivist category.

Another dimension of culture is power distance (Hofstede et al., 1991). Power distance is the level of inequality between the more and less powerful members of society, such as teachers and pupils; and parents and children (Hofstede et al, 1991; Matsumoto, 2000). Larger power distance is associated with more collectivist cultures where inequality is expected and children are taught to be obedient (Hofstede et al., 1991), such as those in Kurdistan.

Uncertainty avoidance is another cultural dimension, which is the anxiety related to uncertain or unknown situations (Hofstede et al., 1991; Matsumoto, 2000). It is suggested that cultures can fall into either weak or strong uncertainty avoidance categories and those in the weak uncertainty avoidance tend to be less anxious and show less emotion and aggression. These characteristics are more associated with individualistic societies, such as the UK. While those in the strong uncertainty avoidance show aggression depending on the situation, perceive different as dangerous and are not risk takers. These characteristics are linked with collectivist societies and cultures (Hofstede et al., 1991), such as Kurdistan.

A further cultural dimension is femininity versus masculinity (Hofstede et al., 1991). A masculine society is where gender roles are clearly defined where men are supposed to be tough and be the breadwinner and women to be modest and concern themselves with dealing with quality of life. Masculine societies are associated with collectivist cultures, such as those in Middle-East including Kurdistan, while the feminine societies, where the genders are expected to have equal responsibility, are linked with individualistic cultures (Hofstede et al., 1991), such as the UK. Whilst the individualism/ collectivism dichotomy has received much attention of researchers, this does not always apply to Hofstede's (1980) other suggestions, such as uncertainty avoidance and feminine versus masculine cultures.

A further concept that defines and divides the societal characteristics is what is known as the honour versus dignity cultures. Dignity is associated with western societies such as Europe and North America, and honour is said to be one of the characteristics of non-western societies such as those in Middle-East (IJzerman, & Cohen, 2011; Uskul, Cross, Günsoy, Gerçek-Swing, Alözkan, & Ataca, 2015). Dignity is defined as the certainty that everyone is born equal and it is not an entity that is given nor can it be taken away by others (IJzerman, & Cohen, 2011), associated with Western societies, such as the UK. An honour culture on the other hand, includes values of family loyalty, high social regard and its members defend reputation through violence (IJzerman, & Cohen, 2011), more prevalent in Middle-Eastern countries, such as Iraq. In honour cultures, the differences between the genders are that a man of honour protects and defends the family, while the women observe the standards set for appropriate behaviour (IJzerman, & Cohen, 2011).

According to the classifications of the individualistic and collectivist category (Hofstede, 2001), the UK falls under the groups of societies within the individualistic and Kurdistan is firmly within the collectivist cultures. Furthermore, the cultures in question are divided by the dignity and honour split, suggesting that differences in what is expected and accepted behaviour and characteristics from its members depend on the beliefs held within the cultural boundaries.

The UK is a developed part of the world and is more advanced in knowledge concerning conditions such as epilepsy (Doughty, Baker, Jacoby, & Lavaud, 2003) and treatment therapies (Kaski & Cockerell, 2015). Furthermore, Western societies are advanced in their pioneering technologies for diagnosis and knowledge of medical conditions (Triandis etal., 1988; Kaski & Cockerell, 2015). Beliefs held by its members are not restricted by familial, religious or cultural boundaries. The British society is such that individuals are free to make life choices based on personal beliefs and not by societal pressures (Kashima et al., 1995; Veenhoven, 1999).

The Kurdish customs in Northern Iraq are quite different to that of the UK's way of life. This difference is perpetuated by the political instabilities in recent decades which are still continuing. Kurdish customs amongst its civilians are very much shaped by its history so it is important to put this in context. Today's Kurdistan is mainly split between Turkey, Iran, Syria and Iraq, and there are some Kurds from Lebanon, and Azerbaijan and Armenia (Meho & Maglaughlin, 2001). Iraqi Kurds, the focus of this research, have had a long history of war and conflict with its central government for many years (van Bruinessen, 2007). Kurds have a long history of nationalistic beliefs which is shaped by its history and struggle to maintain identity (Hassan, 2013). For more detail on the Kurdish history, please also see appendix 16.

Any research from deprived areas, such as Kurdistan, is much needed to advance knowledge further. Although, it is fair to say that dealing with any condition, such as epilepsy, is different for people in Kurdistan as they also have the effects of war and political volatility to deal with at the same time. This research is an important step in reporting studies from an area of little research and will take pride in helping further academic understanding of epilepsy in this region.

In Kurdistan, the family is the cornerstone of society and plays a pivotal role in the life of any Kurd (Meho & Maglaughlin, 2001). As part of their self-identity, Kurdish people generally identify themselves as being part of a larger family and community (Taloyan, Johansson, Saleh-Stattin, & Al-Windi, 2011). The Kurdish culture is bound by tradition and religious rules and women are expected to protect their modesty (Siraj, 2011; Wright, 2014). Muslim women, including those from a Kurdish background, are expected to protect themselves by ensuring they are adequately dressed and are not to wear revealing clothes (Siraj, 2011). This was highlighted in a study carried out in the UK among Iraqi Kurdish women (Wright, 2014). This is relevant for people with epilepsy, as during a seizure, it is expected that people lose control of themselves physically which could make women, from some ethnic groups, even more vulnerable.

Due to the political and economic structure of the area, the health care system in Kurdistan receives little resources for the care of its population (Tawfik-Shukor & Khoshnaw, 2010). It has been reported that people with mental health problems, which in this region could include those with epilepsy due to the health care structure, have reported that almost 50% sought help from an indigenous healer before attending medical centres for advice on their condition (Rahim, Saeed, Farhan, & Aziz, 2015). Although, it is important to mention, this type of healing is not part of the legitimate health care structure, and is not regulated in any part of Iraq, including the Kurdistan region. Indigenous healers are more associated with low to middle income countries. The reasons why people with epilepsy in Kurdistan may attend indigenous healers could be related to the scarcity of adequate health systems in this region. The majority of healing practices of Kurdish people with mental health issues are suggested to be praying and reading the Quran (Rahim et al., 2015).

In the developing countries, it is suggested that people with epilepsy are less well educated due to high school drop outs (Ahmad, 2011). This is mostly down to parents trying to protect their children from the reoccurrence of an epileptic seizure outside the home (Ahmad, 2011). In the developing countries, seizures in public may be harmful socially as well as physically (Ahmad, 2011). Furthermore, people with epilepsy are reported to experience high levels of stigma (stigma and its factors are discussed further in chapter three) due to having a condition such as epilepsy (Ahmad, 2011).

A UK study looking at people with and carers of people with epilepsy from different religious backgrounds explored beliefs about the condition from the perspective of South Asian origin (Ismail, Wright, Rhodes, & Small, 2005). It was found that participants in this study who were from a Muslim background in the UK believed that it was God’s will that they had epilepsy and acceptance came from the comfort of that thought process. The Sikh religion was found to have grounded its beliefs on the basis that epilepsy was punishment for acts carried out in a previous life. Furthermore, elderly people, from all religious backgrounds, had the traditional misconceptions about epilepsy and had little knowledge of the condition (Ismail et al., 2005).

Snape et al. (2009) have suggested that participants in a study carried out in China report that people are well informed on epilepsy as a condition, including familiarity with its symptoms, however, they are not so well informed on the causes of the condition. In Africa people refer to epilepsy as the ‘burns disease’ because of the number of people seeking burn treatment as a result of people with epilepsy falling on fires when they experience a seizure (Baker, 2002).

People’s views may have a great impact on how a person copes with epilepsy and how they are accepted into society. It is crucial that research does not just concentrate on those with the condition but also the level of knowledge, views and attitudes of the general population in relation to epilepsy and people with the condition. A study which was a door to door survey of 1,546 households in Ethiopia explored the general public’s knowledge and attitudes concerning people with epilepsy (Tekle-Haimanot et al., 1991). The results of the study showed that 89% of the participants had heard about epilepsy, 86% had witnessed a seizure, 75% stated they would not employ someone with epilepsy, whilst 58% said they would not be friends with someone with the condition. Their findings showed that people were generally sympathetic in regards to people with epilepsy but had misconceptions about the condition itself. Respondents reported negative attitudes when having to share accommodation or having physical contact with those with epilepsy, especially during a seizure in fear of catching the condition (Tekle-Haimanot et al., 1991). A criticism which may be warranted about this study is the report that 86% of the respondents were illiterate. Improved knowledge of epilepsy is associated with high levels of education (Doughty et al., 2003), and better knowledge may help reduce negative attitudes and stigma in regards to people with epilepsy.

Another very relevant study was carried out in India by Gourie-Devi, Singh, and Bala (2010). Gourie-Devi et al. (2010) attempted to find out the level of knowledge, attitudes and practices of people with epilepsy in Delhi. Their results showed good knowledge amongst people with the condition and positive attitudes when it comes to marriage and children. On the other hand, participants felt that epilepsy was caused by supernatural powers and sins committed by the patient or their ancestors. Gourie-Devi et al. (2010) also stated that due to the religious backgrounds of the majority of people in India, misconceptions of epilepsy are held which affects management of the condition and the treatment gap. Having said that, they suggested having religious beliefs may have a positive effect on patients as it may help by reducing stress in accepting their condition and have the perception of control over seizures (Gourie-Devi et al., 2010). This is an important piece of research as references are made to different beliefs held by people in developing countries as they could be linked to stigmas experienced by people with epilepsy in countries outside the Western societies (WHO, 2010). It is also very relevant to the current research. Treatment is not always sought mainly due to the misconceptions about epilepsy that are held in some countries (McCagh, 2014).

The overall understanding of the types of epilepsies, recognising the symptoms, triggers, and treatment therapies have evolved over time and are developing still. This is not the reality in developing countries (Scott, Lhatoo, & Sander, 2001). There is a lack of reported research regarding the stigma experienced by those diagnosed with epilepsy, and the perception of those without the condition in the developing countries (WHO, 2010). Research is essential in this area to help gain a better understanding of these experiences (WHO, 2010) from the perspective of the person diagnosed and the views of others in society.

The highest epilepsy incidence is reported from the developing countries (WHO, 2010), it is essential that new knowledge and research is directed to these parts of the world. As it is also reported that a high number of epilepsy cases in the developing countries are not adequately treated (Scott et al., 2001), it is more important now than ever to understand the gaps in knowledge and the treatment of people with epilepsy, especially in the developing countries, as this may have a significant effect on the quality of life and the stigma experienced by those with the condition (quality of life is further discussed in chapter two). The UK is known for its diversity in cultural richness through the prevalence of different communities. This research will bring to the surface the importance of highlighting these societal differences in how people with epilepsy are perceived. The outcome of this research will be an important contribution to discovering new data and creating a firm foundation for more research to be conducted in this area, especially in the Middle-East. It is also hoped that the outcomes can help policy makers and provide support for people with epilepsy in these areas.

There is limited availability of literature from other societies and countries in the developing world, consequently suggestions have been made for further research to be undertaken as epilepsy and its associated factors have been shown to impact on quality of life (Tedrus, Fonseca, & Carvalho, 2013). It is important to mention that, to the author’s knowledge, there is no published research on the effects of epilepsy on a person with the condition and very little is known about others’ perception about the condition in Kurdistan in Northern Iraq. This has led to literature search in neighbouring societies in Middle-East with similar values and the use of anecdotal evidence.

Dr Omar (Head of Sulaimania Psychiatric Hospital, Appendix 15) was able to give an anecdotal view on epilepsy and its effects on those diagnosed with the condition in Kurdistan (please see appendix 15 for transcribed interview). Dr Omar stated that because of the societal structure, those diagnosed with epilepsy are considered abnormal by their family and protected at home. Dr Omar also explained that the society functions, not based on personal views, but rather people live for the name of the family and their role in the community. The consequences of an epilepsy diagnosis include a negative impact on schooling, employment and relationships. Stigma was stated to be one of the key issues surrounding this condition. Dr Omar also stated that marriage prospects are negatively affected and the issues of disclosure and non-disclosure arise as a result.

As existing research suggests, the experience of epilepsy may be different for people from different countries (WHO, 2003, 2010; Fernandes, Noronha, Sander, & Li, 2008; Mbuba & Newton, 2009), this study was carried out in the UK and Kurdistan to further explore this issue. The rationale for this was that Kurdistan is from a developing part of the world compared to the UK. This research will explore these two regions to investigate whether there is a difference in how participants feel about their epilepsy and what effects, if any, this may have on stigma and their quality of life. This will give an understanding of how stigma is influencing quality of life in two different contexts. To gain a full picture of the experiences, the views of those without epilepsy will also be explored.

Chapter 2: Quality of Life

This chapter will present the long term impact of chronic illness on quality of life, in particular, epilepsy. The predictors of quality of life will be explored and the theoretical underpinning of this present research will be examined. Quality of life will also be looked in relation to other societies

Quality of life literature was sought in order to gain a better understanding of the concept itself and how individuals in society interpret this perception in relation to their life. A review of published literature was carried out using available resources and databases provided by Brunel University London. Academic Search Complete, Science Direct, PsycINFO, PubMed, and Scopus databases were searched. Google Scholar was also used to gain a wider access to published literature and was able to use these references with the Brunel login details. The keywords used to search for literature in this research were quality of life, quality of life in epilepsy, quality of life in people with epilepsy, quality of life and epilepsy, epilepsy and quality of life, factors influencing quality of life, impact of epilepsy on quality of life, quality of life in people with epilepsy, health related quality of life in epilepsy, quality of life and well-being in epilepsy, adjustment and quality of life, quality of life in neurological illnesses, quality of life and chronic conditions in the UK/Europe/Middle-East/ Developing Countries/ Developed Countries/ Iraq/ Kurdistan/ Iran/ Turkey/ Kuwait/ Saudi Arabia and Jordan. The criteria for the literature search included all studies reporting on epilepsy and quality of life in adults, particularly those reported from the UK and Middle-East. Literature that did not report on the quality of life in epilepsy was not included unless used in studies where comparisons were made between chronic conditions.

Quality of life has previously been debated and defined based on two different perspectives, according to Schalock and Felce (2004). These are social and psychological factors (Schalock & Felce, 2004). The social elements of quality of life include environmental factors such as, living standards, friendships, health and education (Schalock & Felce, 2004). The psychological elements of quality of life are the individual’s interpretations of the social factors which are measured by well-being and happiness (Schalock & Felce, 2004). Another perspective that has been highlighted in literature in regards to health and illness is the biopsychosocial approach, taking into account the condition a person has been diagnosed with, within the context of his environment or society (Engel, 1977). Furthermore, the biopsychosocial approach takes into account all aspects of a diagnosed condition from the person's subjective perception of the illness, including social to medical and psychological viewpoints (Borrell-Carrió, Suchman, & Epstein, 2004; Elliott & Richardson, 2014). A combination of all the explanations in regards to health and illness appears to be interpreted by the World Health Organisation (WHO, 1994, 1997) which suggests that quality of life is understood to mean a good standard of living from a physical, social and psychological well-being and having positive prospects and outlook on life (Saxena & Orley, 1997).

Furthermore, the WHO has defined quality of life as a personal understanding of a person's position in their life, from their cultural background perspective, to the context of their life expectations and objectives (Kuyken & Orley, 1994). An alternative interpretation of quality of life has been put forward as a combination of life contentment, general happiness and subjective well-being which are all closely linked to the meaning of quality of life (Phillips, 2006). However, another perspective argues that individuals' understanding of happiness is not always easy to define as people are not always certain or aware when they are happy (Kahneman, 1999; Kahneman, 2003). In addition, happiness is about the outcome of collective weighing up of experiences, which demonstrates 'objective happiness' (Kahneman, 1999; Kahneman, 2003).

Objective happiness is the observation of experiences in the present, whereas, subjective well-being is the evaluation of past experiences from memory (Kahneman, 2003). Another view of subjective well-being is that it is an important variable as the meaning is understood to be interconnected to quality of life (Huppert & Whittington, 2003; Phillips, 2006; Camfield & Skevington, 2008). A more comprehensive definition that has been put forward to explain subjective well-being states that it is an evaluation of one's life which takes into account life satisfaction, and the experiencing of low moods and happy emotions (Diener & Oishi, 2002; Linley, Maltby, Wood, Osborne, & Hurling , 2009). An interpretation of objective happiness is having a purpose in life, self-acceptance, positive relationships and personal growth (Ryff, 1989; Linley et al., 2009). Objective happiness is sometimes referred to as psychological well-being in most published literature.

Ill health, including epilepsy, stroke and cancer, has been shown to affect subjective well-being (Binder & Coad, 2013). In cases of refractory epilepsy where it has been found that the inability to control seizures with medication affects a person's overall quality of life (Sancho et al., 2010). Uncontrolled seizures could interfere with employment, and since it has been found that people with epilepsy who are in full time employment report better well-being, this could impact on overall quality of life (Collings, 1990). In contrast, insecurity over diagnosis, seizure occurrences and seizure frequency have been found to negatively impact on well-being (Collings, 1990).

It has long been suggested that financial security has no impact on well-being and even the multiplying of your wealth by thousands does not influence the level of well-being a person can feel or report to feel (Bentham & Bowring, 1843). Therefore, financial growth does not always equate to better subjective well-being (Diener & Oishi, 2000). It is proposed that income has little effect on well-being (Deiner, Suh, Lucas, & Smith, 1999), as the increase in income does not necessarily mean that more time is dedicated to the activities that are associated with subjective well-being (Kahneman, Krueger, Schkade, Schwarz, & Stone, 2006). Furthermore, subjective well-being and monetary values are more highly correlated in poorer countries compared to more developed and economically stable societies (Diener, Oishi, 2000; Diener & Biswas-Diener, 2002). Having said that, financially poor Latin Americans do not show especially low subjective well-being (Diener & Oishi, 2000) and even a developing country, such as India, do not report on being less happy, through measures of subjective well-being (Diener, 2000). However, low socioeconomic status, in developed and developing countries, has been reported to be a significant predictor of quality of life in people with epilepsy (Alanis-Guevara et al., 2005). Nevertheless, it is proposed that economic means should be looked as a possibility to improve quality of life and not be accepted as a main predictor (Costanza et al., 2007).

For the purposes of this thesis, a combination of the definitions as set out by the biopsychosocial approach (Engel, 1977) and the WHO (1994, 1997) will be used, as they both take into account similar factors affecting quality of life.

2.1. Adjustment and Coping with Illness

Epilepsy is part of a group of conditions that are chronic (ILAE, 2014). Adjusting to any chronic condition is an important factor to consider when looking at its effects on quality of life. There are many models attempting to clarify how people cope with illness, each with its own interpretation of how this process evolves. Approaches to understanding health and illness as proposed from the *Biomedical* perspective, concentrates on the physiological aspects of illness but ignores the individual, environmental and psychological aspects influencing adjustment (Walker, Jackson & Littlejohn, 2004). The *Biopsychosocial* approach takes into account the biological aspects of illness as well as the psychological and social factors to explain health and illness (Engel, 1977). The *Biopsychosocial* approach is a more fitting approach when looking at epilepsy as it considers other factors affecting the individual and not just the physiological characteristics.

Models from the *Psychosocial* perspective explore illness adaptation includes many factors influencing illness management, including personality traits, external stressors, physical adjustment and coping strategies (Walker et al., 2004). The psychological models of adjustment, which includes *The Cognitive Adaptation Theory*, states that from the diagnosis of a chronic condition, people try to search for meaning from the experience. Furthermore, they try and gain a sense of mastery and control to restore their self-esteem (Taylor, 1983). These are all elements that contribute to quality of life. The *Disability Centrality Model* measures the importance of three main domains on overall quality of life including impact of the condition, perceived control and satisfaction (Bishop, 2005). It is proposed that using this model to assess those with chronic conditions can give a good indicator of an overall quality of life (Bishop, 2005). This model highlights factors of quality of life in regards to illness, and appears to be a better fit for conditions such as epilepsy; however, environmental factors are not accounted for. Apart from the *Biomedical*

Model, the other perspectives take the individual and the environmental influences into consideration, however, no one model fulfils all the factors necessary to explain adjustment in a neurological condition, in particular epilepsy.

It is argued that the way individuals identify with the meaning of quality of life can change over time, especially when a diagnosis of a chronic condition has been given, and that change in understanding can help manage expectations and the condition (Sprangers & Schwartz, 1999). It is further proposed that barriers to adjustment in chronic conditions are low socioeconomic status and deprivation (Stanton, Revenson, & Tennen, 2007). Socioeconomic status has also previously found to be a predictor of quality of life (Alanis-Guevara et al., 2005).

It is reported that the majority of people with epilepsy who do not adhere to prescribed medication for their condition have poorly controlled seizures which can lead to anxiety and low moods (Jones, Butler, Thomas, Peveler, & Prevett, 2006). Lack of adherence to medication and poor seizure control has been associated with perceiving epilepsy and its treatments negatively (Jones et al., 2006). Lack of medication adherence has further been associated with poorer perception of quality of life (Hovinga et al., 2008). In order to manage chronic conditions, such as epilepsy, suggestions of regular check-ups carried out by the medical profession have been made (Jones et al., 2006). As reported, epilepsy has psychosocial effects on people with the condition, and self-esteem can be affected with a diagnosis of epilepsy (Jones et al., 2006). However, it has been reported that a diagnosis of a chronic condition can have a positive influence on self-esteem should the individual be able to accept and manage their condition (Hills & Baker, 1992).

A study by Mirnics, Bekes, Rozsa, and Halasz (2001) used the Washington Psychosocial Seizures Inventory and found that the role of family is very important in coping and adjusting to epilepsy. Social support has been found to have a positive influence in illness management including diabetes and epilepsy (Gallant, 2003). It has been reported that self-efficacy plays an important role in self-management, depressive symptoms, seizure severity and social support are important variables in a persons’ management of their epilepsy (DiIorio et al., 2006). The nature of epilepsy is that sometimes one type of treatment or therapy is not successful and in these cases the treatments can be mixed, for example the use of Vagus Nerve Stimulation (VNS) and anti-epileptic drugs (AED) in order to reach seizure freedom, as this is the main objective, for its positive impact on quality of life (Brodie & French, 2000). However, even with treatment therapies only 70% of people with epilepsy can enjoy seizure freedom, in which case the other 30% continue to have seizures and have this negatively impact on their quality of life (Duncan et al., 2006).

A literature review by Liveh, Wilson, Duchesneau, and Antonak (2001) looked at the psychosocial adaptation in coping strategies. They suggest that coping with epilepsy as a chronic condition may involve patients to use avoidance, denial, self-blame and distraction (Liveh et al., 2001). They also suggest, that because of the stigma attached to people with epilepsy, this affects those with the condition in their daily life, such as employment and life experiences (Liveh et al., 2001). They do conclude that further research is definitely needed to gain more insight into the psychosocial adaptations and coping strategies adopted by people with epilepsy (Liveh et al., 2001). Furthermore, it has been suggested that people with epilepsy may experience severe issues when adjusting to their condition and may need further interventions to improve quality of life (Kemp, Morley, & Anderson, 1999).

In a neighbouring region in Iran, a study looked at coping methods used by people with epilepsy (Hosseini, Sharif, Ahmadi, & Zare, 2010). 21 participants with epilepsy were interviewed using semi-structured interviews and data analysed using content analysis. The results showed that, as a majority Muslim country, most of the participants stated that they used religious activities, such as praying and reading the Quran, to help them cope with their condition. Although, participants had expressed that the role of their family was crucial for emotional support and to help them adapt to their epilepsy, many felt their families were ashamed of them because of their condition. As far as social and governmental support was concerned, the study highlighted the need to raise awareness of epilepsy to increase understanding of the condition in the Iranian society (Hosseini et al., 2010). Nonetheless, positive steps were taken in terms of medication for people with epilepsy in Iran, as it was reported that around 72% adhered to prescribed medication to control their symptoms (Asadi-Pooya, 2005).

In a Korean study which included 178 participants recruited from university hospitals looked at concerns of living with epilepsy (Choi et al., 2011). Participants were aged 18-70 and diagnosed for over one year with any type of epilepsy (Choi et al., 2011). The results of the study showed that people with well controlled epilepsy still worried about the condition being inherited (Choi et al., 2011) which may affect marital prospects. This insecurity regarding epilepsy may be due to the level of knowledge about the condition and how accepting the society is.

A study presented by Amir et al. (1999) looked at the effects of psychosocial variables, mastery and social support, as mediators between seizure severity and quality of life. They found that when a person feels that they are in control of their seizures, they were less troubled with their epilepsy, as the lack of control over seizures presents a great deal of anxiety for those with the condition. The support a person with epilepsy receives may help with the perception of the ability to cope, which in turn helps actual coping. In these cases, self-efficacy and mastery also play a role on how a person may cope with a diagnosis of epilepsy. Amir et al. (1999) reported that the more severe a person with epilepsy perceives their symptoms to be, the less support they claim to be given. They also propose that the more support a person with epilepsy receives the more they feel in control, and their sense of mastery is increased. They include in their discussion that the perception of coping with a condition inspires actual coping (Amir et al., 1999).

Amir et al. (1999) concluded by suggesting that there has to be a certain amount self-efficacy amongst people with epilepsy in order to cope with their epilepsy and improve their quality of life. They continue on by suggesting that the patients' support network should be involved in the treatment process in order to give better support to people with epilepsy, as this can help achieve a better quality of life. In treating a person with epilepsy, it is important to have support groups and counselling in order to increase self-efficacy which in turns leads to a sense of control, locus of control, over the condition (Amir et al., 1999). In order for those experiencing chronic conditions to have an improved quality of life, the need for better self-management is essential, which can then help with perceived control over symptoms (Bishop, 2005). Further proposals are made in relation to health care professionals to be able to offer a complete support network on how people with epilepsy can manage their condition (Ahmad, 2011). Support can be in the form of treatment and help in maintaining an active lifestyle (Ahmad, 2011).

There are other conditions which may be similar to epilepsy in that they are also chronic and need constant management. In such conditions such as asthma and diabetes, it is found that barriers to management of chronic conditions are lack of information and the physical symptoms of the condition (Jerant, Friederichs-Fitzwater, & Moore, 2005). It has further been shown in asthma patients that education about their condition (Gallefoss, Bakke, & RSGAARD, 1999) and well managed symptoms (Hyland, Finnis, & Irvine, 1991) have a positive impact on quality of life. It has been suggested that where chronic illnesses are concerned, conditions such as prostate cancer and hyperlipidaemia, possibly due to these conditions not having too many physical or painful symptoms, quality of life can be compared with that of a physically healthy individual (Schlenk et al., 1997). This comparison is made with illnesses with the lowest quality of life reports such as Acquired Immune Deficiency Syndrome (AIDS), Chronic Obstructive Pulmonary Disease (COPD), incontinence and fibromyalgia (Schlenk et al., 1997).

2.2. Quality of Life Theories

With a diagnosis of a chronic condition, such as epilepsy, it is suggested that quality of life is negatively impacted due to the effects of the condition and its related symptoms (Bishop, 2005). Health related quality of life was investigated in people with chronic conditions such as diabetes, epilepsy and multiple sclerosis using the RAND 36-item survey (SF-36), (Hermann et al., 1996). This was a reasonably large study, including n=271 with epilepsy, multiple sclerosis n=85 and those with diabetes n=555. Participants with multiple sclerosis reported worse off quality of life compared to people with epilepsy and diabetes (Hermann et al., 1996).

Particular symptoms associated with epilepsy, such as seizures, have been noted as important issues negatively affecting quality of life of people with the condition (Taylor, Sander, Taylor, & Baker, 2011). Factors affecting people with epilepsy, such as education, employment, and lifestyle, is influenced by the symptoms of the condition (Fisher et al., 2000). Other factors of an epilepsy condition are the longevity of the condition and the number of therapies needed for the control of the symptoms, which also negatively influences quality of life (Yue et al, 2011). To explain the depth of the effects of chronic conditions on quality of life, theoretical models have been put forward to explain the mechanisms a person goes through in order to deal with a chronic diagnosis.

A theory that has been suggested to explain the impact of health related quality of life is put forward by Gallop et al. (2010). This theory considers the impact on quality of life of those diagnosed with a rare type of epilepsy, Lennox-Gastaut Syndrome (LGS), and their caregivers. In their study 40 parents of children with Lennox-Gastaut Syndrome were included, from the UK, Italy and US. Using semi-structured interviews and thematic analysis, a conceptual model was presented which highlighted the complicated relationship between the symptoms of Lennox-Gastaut Syndrome and its impact on quality of life. This theory has shown that the impacts of Lennox-Gastaut Syndrome are not only disadvantageous to those with epilepsy but also for the caregiver (Gallop et al., 2010).

One of the main factors that emerged was that seizure occurrences negatively impact people with epilepsy and were further responsible for its negative effects in social situations, such as friendships and socialising (Gallop et al., 2010). Caregivers reported feelings of anxiety in anticipation of seizure occurrences and worry their child may not survive further episodes. Parents of children with Lennox-Gastaut Syndrome also reported not being supported by friends and family for childcare duties, depending on the severity of their child’s seizures. The outline of their model includes the physical and cognitive features of Lennox-Gastaut Syndrome, followed by treatments and its effects on the features of Lennox-Gastaut Syndrome and quality of life. The next stage is the external factors which may be positive or negative and the psychological elements of Lennox-Gastaut Syndrome. According to this model, all components appear to directly or indirectly influence the outcome of health related quality of life (Gallop et al., 2010). The model presented is a combination of feedback from both those with epilepsy and carers of those with the condition. Whilst this model offers a useful insight into the impacts of epilepsy on quality of life in Lennox-Gastaut Syndrome, it has failed to differentiate between the carrier's perspective and that of those with the condition. It is unclear how and in what context this model can be utilised to its full potential.

A further health related quality of life theory is proposed by Wilson and Cleary (1995). Their model takes into account the impact of biological and physiological factors as the furthest away from influencing quality of life. Factors with more impact on quality of life are the symptoms of the condition, followed by functioning and general health perceptions. Aside from the biological mechanisms of the condition, all the other stages are shown to be affected by individual and environmental factors. This model proposes that quality of life is also affected directly and indirectly by the factors in this model, however, the biological and physiological functioning have the least impact on quality of life (Wilson & Cleary, 1995). This appears to be a good model for measuring quality of life; however, it is not specific to epilepsy and does not take into account the importance of biological and physiological factors that may be specific to certain conditions, such as epilepsy. Furthermore, this model may not be suitable for measuring quality of life in epilepsy as the symptoms of the condition, such as seizures, are central to the condition, and according to this model they have the least impact on quality of life. Another observation of this model is that the stages are very defined and rigid and does not allow for flexibility between the variables affecting the overall quality of life. Instead, the model appears one directional, working its way from the beginning of diagnosis to the end, which is quality of life.

A revision of the health related quality of life model as presented by Wilson and Cleary (1995) was made to make for a simpler tool to use (Ferrans, Zerwic, Wilbur, & Larson, 2005). The changes proposed highlighted that, firstly, biological functioning is affected by individual and environmental factors and is not a constant variable. The second change proposed removing non-medical aspects, as the authors felt these were all covered either in the environmental or individual factors and finally removing labels on arrows as to not restrict the relationships between the variables (Ferrans et al., 2005).

The WHO (2003) proposed International Classification of Functioning, Disability and Health (ICF) for non-fatal health conditions such as diabetes, depression and schizophrenia (Üstün, Chatterji, Bickenbach, Kostanjsek, & Schneider, 2003). This model is praised for its consideration of social, political and environmental assessments for gathering data on world populations (Üstün et al., 2003). The WHO (2007) in a further model of Classifying Functioning Disability in Children and Adolescents considered personal and environmental factors in the effects of health conditions, including participation, body functioning and activities on the overall quality of life. This model considers many factors that could impact on the overall quality of life of people, including social and political influences, however, it is not specific to neurological conditions, and in particular epilepsy which is unique in its characteristics and treatment.

A systematic review of all available health related quality of life models have been presented by Bakas et al. (2012). In their analysis they have concluded that Wilson and Cleary (1995), revision of Wilson and Cleary's health related model (1995) by Ferrans et al. (2005) and the WHO (2007) in their Classification of Functioning Disability models for Children and Adolescents are good models to use. They have further proposed researchers should use one of these three models for research into health related quality of life, unless there is strong support not to, as they cover essential areas of research (Bakas et al., 2012).

2.3. Predictors of Quality of Life in Epilepsy

Generally, it is accepted that people with epilepsy tend to have lower quality of life compared to people without the condition (Jacoby & Baker, 2008). It has been found previously, that relationships and support from family (table 1) have been factors identified with quality of life in people with epilepsy (Bishop & Allen, 2003). Social support, religion and spirituality and leisure activities all closely follow in their significant impacts on quality of life (Bishop & Allen, 2003). Reports of poorer quality of life in epilepsy are exacerbated by symptoms of the condition as they can have a great impact on everyday activities (Tedrus, Fonseca, & Carvalho, 2013). This detriment to quality of life in epilepsy is a result of direct and indirect negative impacts of the symptoms of the condition (Bishop & Allen, 2003). Direct effects include the physical restrictions and limitations (table 1) as a result of an epilepsy diagnosis (Bishop & Allen, 2003). The indirect impacts of epilepsy include psychological well-being, such as depression and anxiety (table 1), on quality of life (Bishop & Allen, 2003).

A Saudi study included 276 participants looked into quality of life in epilepsy has shown that people with the condition have considerably poorer quality of life compared to the general population (Ohaeri, Awadalla, & Farah, 2009). People with epilepsy are more likely to be uneducated, young, and unemployed, however, if the participants were educated, in employment and married, an improvement was observed in quality of life (Ohaeri et al., 2009). Another study carried out in Basra city in Iraq also showed that quality of life was compromised among people with epilepsy compared to the general population (Shakir & Al-Asadi, 2012). Further findings showed that people with epilepsy were more likely to be less well educated, unemployed and unmarried. Better quality of life amongst people with epilepsy was associated with higher education, family income and being young (Shakir & Al-Asadi, 2012). A Turkish study reported that people with epilepsy demonstrated that their quality of life was poorer compared to those without epilepsy, except in cases where those with the condition had generalised seizures, were married and not taking too many different types of medication (Giray, Ozenli, Ozisik, Karaca, & Aslaner, 2009).

It is a fact that the symptoms of epilepsy are very unpredictable and cause much anxiety and stress (Jacoby, 1992). It is noted that poor seizure control and poor psychosocial well-being were associated with people with epilepsy (Collings, 1995) and were found to impact on quality of life. In newly diagnosed people with epilepsy, loss of physical control was noted to affect those with the condition (Velissaris, Wilson, Saling, Newton, & Berkovic, 2007). Furthermore, fear of seizure recurrence was followed by anxiety (Velissaris et al., 2007). In an American sample, inclusive of n=87 people with epilepsy, it was found that those with the condition reported anxiety and depression related to their condition (table 1), which was found to have a negative impact on quality of life (Johnson, Jones, Seidenberg, & Hermann, 2004). An Iranian Kurdish study has shown that anxiety is one of the biggest factors facing people with epilepsy (Maroufi, Khomand, Ahmadiani, Alizadeh, & Gharibi, 2014).

Seizure frequency has been reported to be one of the main predictors of quality of life in people with epilepsy (Alanis-Guevara et al., 2005; Guekht et al., 2007), and it is suggested that seizure freedom is necessary before improvements to quality of life are observed (Birbeck, Hays, Cui, & Vickrey, 2002). Although, even with a period of freedom from seizures there is still a fear that seizures can reoccur at any time and it is this lack of control over the symptoms that distress people with epilepsy (Jacoby, 1992).

Seizure severity is another variable that has been found to impact on the quality of life of people with epilepsy (Harden et al., 2007; Bautista & Glen, 2009; Sancho et al., 2010; Taylor et al, 2011; Milovanović, Martinović, & Tošković, 2014); meaning that the perception of quality of life is reduced with more severe seizures. Furthermore, seizure severity has been directly associated with anxiety (Sancho et al., 2010). It is also worth mentioning that seizure severity has also been found to have negative effects on self-esteem (Leidy, Elixhauser, Vickrey, Means, & Willian, 1999).

It is suggested that people with epilepsy also experience depression (Taylor et al, 2011; Fiest et al., 2013) anxiety (Johnson, Jones, Seidenberg, & Hermann, 2004) and low self-esteem which consequently negatively impacts on quality of life (Ahmad, 2011). Where refractory epilepsy is concerned, depressive symptoms and seizure worry have been found to have the most impact on quality of life (Loring, Meador, & Lee, 2004). In a recent study from Washington, it was discovered that seizure factors and quality of life were not such strong predictors when it came to suicide in people diagnosed with epilepsy but depression was significant in its prediction

(Hecimovic et al., 2012). This is a significant finding as suicide has been known to be higher in people with epilepsy compared to the general population (Hecimovic et al., 2012).

Learned helplessness has also been linked with depression in people with epilepsy (Endermann, 1997; Rosenbaum, 1984). In epilepsy, learned helplessness is best defined in the context of the inability to control seizures; this is where the person shows signs of giving up (Mikulincer, 2013). It has been shown that lack of control over seizure occurrence and the severity of seizures consequently leads to feelings of helplessness (Devillis, Devellis, Wallston, & Wallston, 1980; Mikulincer, 2013). It is suggested that helplessness is the outcome of irregular experiences and events (Devillis et al., 1980; Mikulincer, 2013), and uncontrolled and unpredictable seizures are perfect examples of this. It is suggested that there is an element of similarity between epilepsy and learned helplessness, where the continuous and uncontrolled seizures can lead a person with the condition to feel helpless towards the symptoms they experience (Rosenbaum, 1984; Amir et al., 1999).

A study carried out in Mexico has identified four variables that have been found to be significant predictors of quality of life. In epilepsy, sleep disturbance, being female, seizure frequency and socioeconomic status (table 1) were all factors found to negatively impact quality of life (Alanis-Guevara et al., 2005). In recent literature, it is further confirmed that females tend to report lower quality of life compared to males (Tedrus et al., 2013). Further studies have demonstrated that sleep disturbances and deprivation have also been linked to more frequent seizures and in turn lead to poorer quality of life (Matos, Andersen, & Valle, 2010). A study looking at the quality of life of Kurdish people in Iran reported that unmarried people stated that their quality of life as moderate or bad. Further analysis showed that those indicating to have a bad quality of life were unemployed people and housewives (Mofidi, Ghazinour, Araste, Jacobsson, & Richter, 2008).

Many variables have been found to be significant predictors of quality of life, such as well-being, self-efficacy and locus of control. Locus of control was first introduced by Rotter in 1954, in which the notion of internal and external locus of control was introduced as predictors and affecters of performance (Julian & Katz, 1968). Locus of control refers to the individuals’ perception of power on an outcome (Kessler, 2013). Internal locus of control is the individuals’ belief in the personal control affecting a desired outcome (Kessler, 2013). External locus of control, on the other hand, are factors outside the individuals’ control, such as environment and society, affecting an outcome (Kessler, 2013). In a study comparing those with pseudo-seizures (psychological reaction to external stressors) and people with epilepsy showed that people with pseudo- seizures demonstrated greater external locus of control (Stone, Binzer, & Sharpe, 2004). This was also the case with findings where people with pseudo-seizures were compared to healthy controls, demonstrating external locus of control over health condition (Goldstein, Drew, Mellers, Mitchell-O’Malley, & Oakley, 2000).

As discussed above, there are many factors reported to impact on quality of life in people with epilepsy, table 1 shows a list of known factors associated with the condition.

Table 1: Reported factors impacting quality of life in people with epilepsy

	Factors Impacting Quality of Life in People with Epilepsy
1	Seizures
2	Seizure frequency
3	Seizure worry
4	Seizure Severity
5	Longevity of diagnosis
6	Number of therapies/medication required to control seizures
7	Socioeconomic status
8	Sleep disturbance
9	Sleep deprivation
10	Being female
11	Environmental factors
12	Individual factors
13	Family/social support
14	Spirituality
15	Leisure activities
16	Physical restrictions
17	Depression
18	Anxiety
19	Lack of education
20	Unemployment
21	Marital status (unmarried/unattached)
22	Being a housewife
23	General health perception

The impacts of an epilepsy diagnosis have been linked to factors other than physiological (seizure), and psychological (depression) influences, such as social consequences. It has also been shown that people with epilepsy come across problems to do with marriage, education and social segregation (Baker, 2002). It is further reported that people with epilepsy experience lower employment and marriage prospects because of their condition (Amir et al., 1999). This may be down to the lack of control of seizures, the lack of confidence as a result of uncontrolled seizures and or fear of stigma from others (Amir et al., 1999). The experience of and perceived stigma, together with lack of control of symptoms also impacts negatively on quality of life (Jacoby, 2002; Whatley, DiIorio, & Yeager, 2010; Ahmad, 2011). A study of older people with epilepsy has shown that the perception of stigma as well as seizure frequency had a negative impact on quality of life (McLaughlin, Pachana, & Mcfarland, 2008).

Epilepsy has been understood to affect a person in more ways than one; it can be the defining attribute of a person (Jacoby, 2002) and has been linked to a person's quality of life by negatively impacting on well-being (Diener & Oishi, 2001). Although, it is important to mention in Western societies, knowledge has helped with understanding of this condition, but having a diagnosis of epilepsy can still have a negative impact on stigma and quality of life (Morrell, 2002).

This chapter has highlighted issues affecting and predicting quality of life of people with epilepsy. As explored above, a diagnosis of epilepsy is a difficult one and sometimes challenging to accept. It has been shown that depressive symptoms (Bishop & Allen, 2003; Johnson et al., 2004; Hecimovic et al., 2012) account for the most variance in quality of life, the higher the depression the lower quality of life in people with epilepsy (Whatley et al., 2010). Reports from different societies have shown the implications for those with epilepsy. It has been shown that depression and seizure control are two of the main factors predicting quality of life. Although, it has been suggested that people from different backgrounds can have incorrect information as to what epilepsy is and this may have an influence in how a condition is accepted. Historical views of epilepsy have not been kind in its explanation of the condition, however, in modern times understanding of epilepsy is much clearer and it is the individuals' quality of life that is the main focus of research, as a cure or long term resolution is not always promised by medical professionals. Stigma is another factor reported to affect quality of life, this is further explored in Chapter three.

Chapter 3: Stigma

This chapter will explore the associated stigma that goes hand in hand with a condition such as epilepsy, in that it can be a hidden condition, has misconceptions and a lack of knowledge surrounding it. Furthermore, this chapter will outline the stigma that exists with relation to illnesses and social settings, in particular epilepsy. Stigma can also be perpetuated by where in the world a person lives. This chapter will also look at knowledge of epilepsy and report on culturally relevant literature in this area.

Stigma is defined as the association of shame on a person or situation due to a physical or social deviance to the normal societal acceptance (Goffman, 1963); this can be a physical deformity, illness or mental health issues. Stigma originates from the Latin word *stigmat*, which can be translated as to be marked or branded, and from the Greek translation it means to be tattooed (Morrell, 2002). Stigma is associated with people who are discredited or have a mark on their character (Morrell, 2002) which makes them stand out from the general population as having a physical or mental disability or illness. Furthermore, stigma has been argued to have social associations, what may be stigmatising in one society may not be in another (Yang et al., 2007).

The meaning of illness varies from societies which can influence the way cross cultural research is conducted. Medical diagnoses and treatment needs to be culturally and socially specific as the meaning of illnesses can vary across different societies (Good, 1977). An example of this is further explored in the presentation of the meaning of ‘Heart Distress’ in the Iranian population of Maragheh following a two year field research. The perceived causes of heart distress was reported by the Maragheh residents to be the result of sex, pregnancy and childbirth; general weakness and little blood; worry and anxiety as well as inter-personal problems. Heart distress is concluded, by the researcher, to be the culmination of situations, motives, feelings and stress ingrained in the society of the population of Maragheh. Furthermore, the meaning of illnesses is the result of the association of the issues such as feelings and stresses embedded in the culture of a given society (Good, 1977).

In health, stigma is defined as a social process or experiences where individuals are rejected or devalued for having a particular condition which can be based on experience or anticipation (Weiss & Ramakrishna, 2006). The aims of studying stigma in health has objectives such as, understanding the presence of stigma in different illnesses from a cultural perspective; the differences in stigma and different illnesses; the source of stigma and its effects on health and behaviour; assessing the changes in stigma over a period of time and social change; and to improve knowledge to affects health policies and laws to minimise stigma over time (Weiss & Ramakrishna, 2006).

The development of Explanatory Model Interview Catalogue (EMIC) was influenced by the necessity to combine epidemiological and anthropological research methods for studies into physical and psychological illnesses (Weiss, 1997). The EMIC aims to draw out perceptions, beliefs and practices of a given society in relation to illness (Weiss et al., 1992). Additionally, the inability to generalise the experiences reported by those directly affected by illness from the developed to developing societies further emphasised the need for the EMIC (Weiss, 1997).

The EMIC contains a set of locally adapted interview models based on the experiences of those affected directly by the illness. The model consists of an interview structure and includes variables such as patterns of distress, perceived cause, help seeking and treatment, general illness belief and disease-specific queries. The first variable, patterns of distress, refers to a variety of issues including social restrictions, economic factors and stigma. EMIC includes a detailed section on stigma as it is an essential variable of the distress related to mental health and chronic conditions which can influence illness behaviour and help seeking and treatment. The method of analysis combines qualitative and quantitative methods where semi-structured interviews are cross referenced to check for significant relationships between the variables in the EMIC model (Weiss, 1997). The concept of the development of the EMIC is fitting; however, it is a long and restrictive process of collecting data. The interview model is structured, depending on the society, which leaves little room to manoeuvre. Furthermore, the process of checking the relationship between the variables in the different methods of research also makes it a very time consuming process which makes it unsuitable when resources are limited.

In a study using the World Health Organisation Quality of Life measure (WHOQOL), Quality of Life in Epilepsy Inventory (QOLIIE-89) and Stigma Scale of Epilepsy (SSE) was carried out in India with 45 participants split into three groups (Kumari, Ram, Nizamie, & Goyal, 2009). The first group was newly diagnosed people with epilepsy without any treatment, the second group had been receiving treatment for at least one year and the final group was a control group matched for age (Kumari et al., 2009). The results showed that those with epilepsy have lower scores on quality of life and higher scores on stigma compared to the healthy controls (Kumari et al., 2009). A further comparison between those newly diagnosed without treatment and those receiving treatment for at least one year showed that newly diagnosed people with epilepsy have poorer quality of life (Kumari et al., 2009). This detriment to quality of life is related to the individual's own misconceptions about being diagnosed with epilepsy and the negative stereotypes associated with this condition.

3.1. Stigma Theories

Stigma is a social concern (Link & Phelan, 2006; Benoit, & Shumka, 2009) and in order to define and conceptualise it in regards to epilepsy, it is crucial to understand the roles and responsibilities of the individual and society in its formation. The terms Symbolic Interaction and Role Theory have been used previously to examine the roles of the individual and society independently as well as collectively (Stryker & Statham, 1985). Symbolic Interactionism suggests that an individual is the product of social experiences (Mead & Mind, 1934) and that society consists of rules which nurture the social person and leads to the creation of social behaviour (Stryker & Statham, 1985). Role Theory suggests that individuals tend to behave differently depending on their social situations and their identity (Biddle, 1986). Both of these theories attempts to understand social matters in terms of social developments and the individual experiences of its members, however, they do not offer a complete explanation individually, and instead complement each other to offer a more comprehensive interpretation (Stryker & Statham, 1985). This interaction has been referred to as ‘two sides of the same coin’ by Cooley (1902) (Stryker & Statham, 1985).

A more comprehensive theory to define individuals’ identity is presented by Goffman and what is known as Interactionist Role Theory (Stryker & Statham, 1985). According to Goffman (1969) social situations have been associated with being part of a theatrical scene which needs at least two individuals to play different roles (Stryker & Statham, 1985). The situation that occurs between these individuals are performances between actors and the observers of society are the audience (Goffman, 1969). People (or actors) can have different roles in life to do with their work, family, relationships and so on and dress and portray themselves according to the rules of their situation or society. When entering a situation or scene, there will be an interest in the other person’s socioeconomic status, their attitude towards them and their trustworthiness. This information is important as it can help define the situation and what is expected of individuals in that scene. Previous experiences come into play where knowledge about dress code and social settings can be applied to new situations and this can help with knowing what is expected from individuals. Depending on the type of assumptions individuals want others to make about them, they will portray different characteristics and work hard to create and maintain their identity (Goffman, 1969). To be accepted in a specific social setting, individuals may dress similar to its other members and make an effort to maintain their projected selves in order maintain credibility among others and be considered ‘normal’ (Goffman, 1969). Should this portrayal of the self be interrupted by an undesirable characteristic or omission, the individual could be disgraced and be discredited by those in the group or society (Goffman, 1969).

According to Goffman (1963), epilepsy itself is a ‘discreditable’ condition, but until the person is known to have epilepsy they are not ‘discredited’. This may affect a person with epilepsy in whether they decide to disclose their condition or keep it hidden in order to maintain their identity and keep up with the ‘normals’ of society. It is suggested that everyone is ‘normal’ in society until associated with a negative characteristic such as physical or mental disability or deviant behaviour, which can lead a person to be stigmatised and discredited. Goffman (1963) has identified three types of stigma. The first type of stigma is that of a person with a physical deformity, this is where a physical irregularity, condition or disability could lead to an individual being stigmatised. The second type is suggested to have individual character flaws and have social deviance roots, such as those who are career criminals or deviate from other social rules. Finally, Goffman proposes tribal stigma, which can be any type of stigma that is associated with one’s race, religion or culture (Goffman, 1963).

It is not difficult to associate epilepsy to the types of stigma as proposed by Goffman, in that epilepsy is a somewhat hidden condition and the person with epilepsy may not show any symptoms of the condition, unless they decide to disclose their circumstances. Also, epilepsy is a physical disability but may not show any physical characteristics of the condition and would fit the description of the first type of stigma if the information is shared by the individual or if the person experiences a seizure in public. Epilepsy does not have racial or religious associations which would rule out the tribal stigma and also it is not social deviance behaviour. Having said that, the misconceptions different communities may hold, such as those in the developing regions, could associate epilepsy as a consequence of the actions of those diagnosed with the condition. Furthermore, epilepsy can have associated misunderstandings in that it is sometimes linked with mental health issues (WHO, 2010); this may be the case for people in Kurdistan. As a consequence, epilepsy could come under the second type of stigma which can be associated with an individual’s mental health (WHO, 2010). However, this connotation can only be made when there is a lack of knowledge of what epilepsy is and what it entails, this misunderstanding is more frequent in societies that do not possess accurate or full information on the condition (WHO, 2010).

The notion of epilepsy as a discreditable condition is very much in line with Goffman’s (1963) suggestion, and any person diagnosed with epilepsy is perceived to be ‘normal’ or ‘credible’ until disclosure occurs. Through disclosure, consequently leads people with epilepsy to become discredited in society. To be discredited is when individuals are not treated as ‘normals’ and they are undervalued or dishonoured members of society (Goffman, 1963). Goffman (1963) further explores that communication between the credible and discredited as 'spoiled interactions'. This may push those with discreditable conditions to be a different character to the outside world as if on a stage and not risk being discredited and continue to act like a 'normal' by concealing their character flaws (Goffman, 1963).

Katz (1981) suggests that there is a difference between a person's stigma that is public knowledge and hidden stigma. This would fit into stigma in epilepsy more accurately as the condition, in some cases, can be concealed unless an individual decides to disclose the information themselves (Katz, 1981). This can also be compared to Goffman's (1963) suggestion of epilepsy as a discreditable condition, and people with epilepsy as discredited through disclosure or seizure in public. Katz breaks the process of stigma down to four components, the first being an exploration of stigma from a spectator's point of view (Katz, 1981), this takes into a count others' perception of the stigmatising condition. Secondly, how one could feel threatened by the stigmatised individual, whether there are any harmful effects as a consequence to other individuals (Katz, 1981). This could also be related back to Goffman's proposal of 'spoiled interaction', where depending on the type of society a person lives in, others may want to distance themselves from stigmatised individuals, in order to distance themselves from being associated with a discredited or disgraced individual. Thirdly, whether there is a feeling of pity or sympathy for the individual being stigmatized and lastly, whether the stigmatised individual is accountable for possessing such a condition or characteristics which leads to their stigma (Katz, 1981).

Katz (1981) also puts forward that there are three models which explain stigma and its processes. The first model Katz suggests is the *negative attributes model,* which suggests that certain attributes or characteristics about a person, whether physical, social or familial would result in others forming a negative attitude towards the individual in question. This model is quite similar to Goffman's '*discreditable*' suggestion. The second is *scapegoat model*, which targets certain groups within society for possessing certain characteristics. For example, a certain group may be targeted for the complications in society. This model echoes with Goffman's *Tribal Stigma* as the characteristics of the proposed model are very similar. Finally, the *labelling perspective* suggests that social deviance is necessary but not sufficient for stigmatization to occur, ‘‘it corresponds to a point of view that holds that individuals are disvalued and isolated, less because they display attributes that violate accepted standards than because the majority choose to regard these persons as deviant’’ (Katz, 1981, p. 121). The negative attributes model resonates well with epilepsy in developing countries where this condition affects relations and one’s place in the community (WHO, 2010). Further, when a person is diagnosed with epilepsy in a Kurdish family, the whole family becomes the protective armour to avoid being negatively labelled and not risk social disadvantages.

A diagnosis of a medical condition can be viewed as moving away from the norm of the rest of the population and as identifying imperfections (Scambler, 1998). The *hidden distress model* as presented by Scrambler (1989) aims to explain the diagnosis of an epilepsy condition on a person (Scambler & Hopkins, 1990). This model suggests that stigma experienced as a result of an epilepsy diagnosis can be split into two types, *felt* and *enacted* stigma (Scambler & Hopkins, 1990; Scambler, 1993). *Enacted* stigma is experiencing discrimination as a direct result of having epilepsy, such as a driving ban (Scambler, 1993). *Felt* stigma is the personal shame attached to having epilepsy and not being perfect and more importantly, leading to experiencing *enacted* stigma (Scambler & Hopkins, 1990). This model can be split into three components that explain the personal struggle which arises as a consequence of epilepsy (Scambler & Hopkins, 1990).

The first is the *fear* of enacted stigma as a result of previous beliefs prior to diagnosis that a person may hold based on the teachings of our parents (Scambler & Hopkins, 1990). The second factor is the decision to *conceal* the diagnosis and to be perceived as just another ‘normal’, in fear of being ‘discredited’ (Scambler & Hopkins, 1990). The third component is that as a result of concealment, the effects of *enacted* stigma are not as overbearing as the *felt* stigma experienced by those with epilepsy (Scambler & Hopkins, 1990; Scambler, 1993; Jacoby & Austin, 2007). This model further highlights that *felt* stigma precedes *enacted* stigma in its effects on a person (Scambler, 1998). *Felt* stigma is said to have more negative effects on a person compared to *enacted* (Jacoby & Austin, 2007). It has further been suggested that *felt* and *enacted* stigmas have negative impacts on quality of life (Youn, Hong, & Kwak, 2001). The factors presented in this model are comparable to Goffman's concept of 'discreditable' and the 'discredited' and the pressures on individuals to maintain 'normality' amongst the members of their society or audience.

It is claimed that stigma in epilepsy can be categorised in three levels which are *individualised, interpersonal* and *institutional* (Jacoby & Austin, 2007). Jacoby and Austin (2007) argue that on the *individualised* level, people diagnosed with epilepsy associate the diagnosis of the condition with negative feelings of shame and fear (Jacoby & Austin, 2007). Jacoby and Austin (2007) state that on the *interpersonal* level, the stigma of epilepsy dates back thousands of years through religious beliefs associating seizures with being possessed and sins having been committed. Furthermore, the associated characteristics of epilepsy such as aggression have confirmed stereotypes about the condition and helped maintain stigma (Jacoby & Austin, 2007).

The *institutionalised* stigma refers to people with epilepsy being marginalised by society and bound by legality, with particular restrictions when it comes to employment (Jacoby & Austin, 2007). Those with epilepsy are unable to take up employment with the armed forces, and may also face further limitations when it comes to a teaching career, working for the medical profession, the police force, fire brigade and the prison services (Jacoby & Austin, 2007). It also important to mention that driving bans come into force when it comes to an epilepsy diagnosis and can only be reclaimed after a period of a person being seizure free for a fixed period, this can change depending on where the person lives (Jacoby & Austin, 2007) and the type of epilepsy diagnosed. This model is similar to Goffman's suggestion of the discredited, however, it appears that the discreditation is different depending on the situation, such as being socially discredited (by losing driving license) or individually discredited (such as the shame of having an epilepsy diagnosis).

Dimensions of stigma, as proposed by Jones et al. (1984), has six categories that have to be taken into consideration when dealing with stigmatising conditions. The first is *concealability*, whether the condition can be concealed or noticeable and how much can the visibility be guarded (Jones et al., 1984). The *concealability* category resounds well with Goffman's concept of individuals attempting to appear being 'normal' in their societies and hide their epilepsy in fear of being 'discredited' or a less valued member of society. The second dimension is *course*, whether the sequence of conditions changes and what can be expected as its eventual outcome (Jones et al., 1984). The third is *disruptiveness*, whether the condition in question affects communication and social interactions (Jones et al., 1984). The fourth dimension of stigma is *aesthetic qualities*, this is referring to whether the condition affects how the person looks, and if the person with the condition is unappealing to look at (Jones et al., 1984). *Origin* is the fifth dimension and is referring to how the condition came about, whether the person had any control over getting this condition or not, whether they were responsible for their fate (Jones et al., 1984). The final dimension is *peril* and is concerned with the type of danger or ill effect this condition can have (Jones et al., 1984).

Epilepsy is a condition that can be hidden and so the first dimension is not always up for discussion as the person with epilepsy has the power to conceal their condition in most cases without having to disguise in any way. The *concealability* dimension may be more of an issue with conditions such as cerebral palsy and physical disabilities, such as wheelchair users, as it is more difficult to conceal and the decision is not always in the hand of the person with the condition (Hebl & Kleck, 2000). The second dimension, *course*, is also not very relevant to epilepsy as the course of epilepsy as a condition can stay the same over a long period of time and can go into periods without epileptic seizures. This also means that the condition may not get progressively worse over time.

During periods when a person is experiencing a seizure or absences, *disruptiveness* and *aesthetic quality* could be identified with people with epilepsy. Apart from these instances epilepsy rarely affects social interaction, and facial and or other physical changes are not usually affected (Chadwick & Usiskin, 1992). The dangers associated with an epilepsy diagnosis are mainly towards the person with the condition and not imposed on others (Chadwick & Usiskin, 1992). The *origin* of epilepsy is usually not intentional and the person does not have any powers on being diagnosed with epilepsy (Katz, 1981), apart from cases where alcohol and recreational drugs are involved (Wood et al., 2009). Epilepsy, to the knowledgeable person, is not linked to deviant behaviour and so the *origin* of the condition is not always associated with stigma. However, there is a constant fear of seizing in public and being found out and so the *peril* dimension is relevant as far as stigma is concerned, but only for the person with epilepsy and not others in society. Nevertheless, observing a seizure may be distressing for others to witness.

Reports state that those with epilepsy feel stigmatised because of their condition and, if disclosed, others may not want to be close to them (Kleck et al., 1968). This perception of stigma appears to be a strong argument for people with stigmatising conditions, such as epilepsy, to conceal rather than disclose information regarding their condition to those around them (Jones et al., 1984). A person with epilepsy may then decide whether they would conceal their condition and be just like everyone else and be treated as just another ‘normal’ (Goffman, 1963) or to disclose their epilepsy and be constantly associated with the condition and live up to its negative connotations of their diagnosis (Jones et al., 1984). One of the important factors in epilepsy is that it has little or no physical symptoms, unless it is a secondary condition, the decision to disclose or conceal this condition appears to depend on the society that a person belongs to (Kleck, et al., 1968).

Whilst it is easy to distinguish between most conditions and illnesses, epilepsy is very different in that unless it is disclosed by the person with the condition or a seizure is witnessed it remains hidden, and the decision to disclose is firmly in the grasp of the person with epilepsy (Schnieder & Conrad, 1980). Epilepsy is similar to other hidden conditions such as AIDS and Diabetes (Fernandes et al., 2007a). The difference between whether a condition is visible or not and whether disclosure takes place or not is very much dependent on the amount of stigma anticipated from society (Joachim & Acorn, 2000).

It is the anticipation of stigma that persuades people with epilepsy to conceal or disclose their condition (Kleck, et al., 1968; Schnieder & Conrad, 1980). Schnieder and Conrad (1980) compared disclosing an illness to being in the 'closet' and a decision whether to hide or disclose an epilepsy diagnosis is based on the potential for stigma. It is also recognised that if the environment that individuals inhabit is knowledgeable and accepting of the condition, this could potentially influence 'coming out' (Schnieder & Conrad, 1980).

The fact that epilepsy, in most cases, is a non-fault condition (WHO, 2010) which could make a difference to how much stigma surrounds it (Katz, 1981). It is recognised that with any illness the questions of whether the condition is visible or hidden, the decision to conceal or disclose need to be considered (Joachim & Acorn, 2000; Kleck, 1968). Physical or visible disabilities have an effect on how others interact with the person with the stigmatising condition (Kleck, 1968) and in the case of epilepsy, people with the condition who have well controlled seizures and symptoms may choose not to reveal their condition to significant people in their lives (Kleck, 1968).

3.2. Perception of Others

As previously discussed, epilepsy has been linked to stigma (Tekle-Haimanot et al. 1991; Jones et al. 1984; Doughty et al. 2003; Jacoby & Austin, 2007) due to the misconceptions surrounding the symptoms associated with the condition. Additionally, the degree of stigma experienced is indicated to be dependent on what region in the world a person lives (WHO, 2010, Fernandes, Noronha, Sander, et al. 2008). Research has shown that there is increased awareness of epilepsy in some countries, such as the UK (Doughty et al. 2003); however, some societies lack information and knowledge which reinforces stigma and negative attitudes in regards to people with epilepsy (Jacoby & Austin, 2007). In the developing regions, epilepsy is still associated with misconceptions about its symptoms and there is a lack of knowledge of the condition amongst the medical profession, those with epilepsy and society as a whole (Scott et al., 2001; WHO, 2003). Those with epilepsy in the developing countries experience stigma, which can have a distressing effect on quality of life (WHO, 2010). It is reported that stigma is high in the developing countries due to a lack of understanding of epilepsy and research in these parts. This may have affected the increased level of stigma and poor quality of life for and towards those with the condition (WHO, 2010).

Fernandes et al. (2008) reported on a study carried out in different parts of Brazil, which included 266 participants using the Stigma Scale of Epilepsy (SSE). The results of this study concluded that regional culture affected people’s perception of stigma and negative attitudes concerning those with epilepsy and suggested this condition is stigmatising, which affects people with epilepsy in their daily lives (Fernandes et al. 2008). Fernandes et al. (2008) further proposed that the level of impact on a person with epilepsy may depend on the area that person lives and suggested that it is important to consider cultural and social differences when looking at stigma in epilepsy.

In a further study from Brazil, Fernandes et al. (2004) developed a series of open ended questions to explore the experience of stigma in epilepsy from the perspective of those with the condition and those not diagnosed with epilepsy. The study was carried out with 40 participants from an outpatient clinic in Brazil, 20 of whom were patients with epilepsy and 20 were relatives of the patients. Their questionnaires consisted of 3 main areas, which included medical, social and personal aspects. Fernandes et al. (2004) concluded that perception of stigma was not only an indication of lack of knowledge, but was also, at times, paired with inappropriate behaviour towards those with epilepsy. The lack of knowledge plays an instrumental role in others’ perception of epilepsy and how they interact with people with epilepsy in society (Fernandes et al., 2004).

It would appear that there is a correlation between stigma in countries where epilepsy goes largely untreated. However, the inability to have epilepsy treated in developing countries may also be connected to the point that the condition is not always identified (Mbuba & Newton, 2009).

It is put forward that stereotyping is explained by three approaches that aim to explain the phenomena (Jones et al., 1984). The first is the *socio-cultural perspective*, the second is the *motivational approach* and the final theory is the *cognitive approach* (Jones et al., 1984). The *socio-cultural perspective* postulates that we are a product of the experiences we are exposed to and the information received from those around us, including parents and the media. This theory also investigates how beliefs originate and limit exposure to certain beliefs and false information can lead to incorrect conclusions (Jones et al., 1984). This approach is very similar to how individual identities are formed in society, according to Goffman (1963). The *motivational approach* proposes that social and psychological needs encourage in stereotyping social categories, this is because of our own internal conflict and needs (Adorno, 1950; Jones et al., 1984). The stereotypes may be because we are threatened by these traits in ourselves. The *cognitive approach* argues that stereotyping is a basic feature of our cognitive function (Jones et al., 1984).

A study comparing stigmas concerning people with three chronic conditions were carried out in Brazil where AIDS, Diabetes and Epilepsy were considered (Fernandes et al., 2007a). The results showed that participants perceived diabetes as the least and AIDS had the most stigma attached to it, however, epilepsy was a close second to AIDS which was attributed to lack of knowledge and education (Fernandes et al., 2007a).

Power has been suggested to influence stigma (Link & Phelan, 2001). People need social, economic and political power to be stigmatising in regards to a particular group (Link & Phelan, 2001), in this case epilepsy. It is also suggested that social power is needed for people to be stigmatised towards those who are socially imperfect, for example, missing a limb, being obese or having a mental disability (Link & Phelan, 2001). These imperfections are associated with being weaker and therefore can be the object of stigma (Link & Phelan, 2001). This proposal resonates with Goffman’s (1963) theory where conditions, such as epilepsy, can be ‘discreditable’ conditions and those who are known to have epilepsy are undervalued in society and are imperfect. Stigma is the product of society allowing labelling and discrimination to occur in power situations and this filtering to the rest of the general population (Link & Phelan, 2001).

The experience and perception of stigma is reported from both the developed and developing countries amongst people with epilepsy, although there is a difference as far as *enacted* stigma is concerned (Baker, 2002). As it can be understood from previous studies, not only the person with epilepsy may have fewer life opportunities, but may also be stigmatised by higher institutions by restricting their legal rights (Jacoby & Austin, 2007). In Western societies there is a higher level of knowledge and less negative attitudes towards people with epilepsy, however, in developing regions, such as Kurdistan, this is not the case (WHO, 2010). There is a lack of knowledge amongst people with epilepsy (Long, Reeves, Moore, Roach, & Pickering, 2000) and those without, and negative attitudes are common (Young et al., 2002), and stigma is present.

A large study inclusive of 10 Middle-East countries, including Bahrain (n=200), Cyprus (n=150), Iran (n=942), Jordan (n=407), Kuwait (n=326), Lebanon (n=909), Oman (n=70), Qatar (n=248), Syria (n=245) and UAE (n=343) was carried out and suggested that seizure frequency, stigma and poor quality of life were all issues related to those with epilepsy (Baker, Jacoby, Gorry, Doughty, & Ellina, 2005). This resonates with a European study, showing around half of people with epilepsy feel stigmatised because of their condition (Baker, Jacoby, Buck, Stalgis, & Monnet, 1997). Due to the perception of stigma, people with epilepsy in Iran considered epilepsy as the worst condition to be diagnosed with (Hosseini et al., 2010). A Yemen study has demonstrated that around 20% of university students thought that epilepsy was associated with insanity and was caused by an evil eye. Around 64% of the participants (n=1155) would not agree to marriage with someone with epilepsy and more than 30% would not let their child play with another child with epilepsy (Al-Eryani et al., 2015).

A study carried out in Korea has found that over 30% of people surveyed felt stigmatised by epilepsy and discriminated against as a result (Lee, Yoo, Lee, & Korean QoL in Epilepsy Study Group, 2005). Another study in the Asian region by Jacoby et al. (2008) put forward that there are great misconceptions about epilepsy in China and Vietnam, especially in the case of the hereditary factor that is associated with the condition. This misconception has impacted on the level of stigma in regards to people with the condition and as a result affected the prospects of marriage in these countries for those with epilepsy (Jacoby et al., 2008).

Perceived stigma can have a disabling effect on a person and their quality of life (Ahmad, 2011). It is reported that as a result of a diagnosis of epilepsy people may be kept from education, have lower employment prospects, less opportunities when it comes to marriage (Ahmad, 2011), and ultimately have this affect their quality of life. With a diagnosis of epilepsy also come restrictions on a person's options on how much they partake in everyday life activities. A person with epilepsy may be hesitant to carry out their usual activities that they enjoyed before diagnosis in fear of experiencing a seizure which may in turn make them a target for ridicule and stigma (Fisher et al., 2000). There are also cognitive impairments, such as memory functioning which may negatively impact on an individual with epilepsy (Fisher et al., 2000).

Further issues include problems of inaccurate information and misconceptions regarding epilepsy and its characteristics (WHO, 2010). Families of people with epilepsy in the developing countries also face a certain amount of shame and stigma, as epilepsy has been known to possibly have a genetic predisposition (WHO, 2010). The level of misinformation, lack of knowledge and stigma in the developing countries is high (WHO, 2010). Research is essential in this area to help in improving levels of knowledge and reducing stigma in order for a better quality of life for people with epilepsy and families of those with the condition (WHO, 2010). This suggestion may also help people with epilepsy better manage their condition, help keep them in education, with confidence this may lead to better employment prospects, and more opportunities for marriage, this in turn may reduce perceived and experienced stigma.

3.3. Stigma & Knowledge of Epilepsy

An individual's level of knowledge about epilepsy can impact on stigma concerning those with the condition (Doughty et al., 2003; Tekle-Haimanot et al., 1991). Stigma can have a negative effect on the quality of a person's life (Whatley et al., 2010), and depending on the society in which a person lives can affect how much they understand their condition (Fernandes et al., 2008; Doughty et al., 2003). A study carried out in a developing country, Jordan, found that although people were knowledgeable about epilepsy as a condition, that it is a serious condition, misunderstandings were still present and influenced by the sociodemographic factors (Otoom, Al-Safi, Sequeira, & Alkofahi, 2006).

Doughty et al. (2003) carried out a study concentrating on ten European countries, including over 6,000 respondents. The participants in this study consisted of people with epilepsy and carers of people with epilepsy (Doughty et al., 2003). This was one of the largest studies of its kind which looked at societal differences in knowledge. Their findings were in line with other studies looking at different societies and the level of knowledge possessed. The results showed that people with epilepsy are usually well informed about their condition, nevertheless, there were differences in the level of knowledge between the countries (Doughty et al., 2003). For example, the UK and German respondents scored higher on the knowledge questionnaires compared to those from Portugal and Turkey (Doughty et al., 2003). The authors were able to link higher epilepsy knowledge to a greater level of education, longer period of the condition, higher scores of stigma and seizure type (Doughty et al., 2003).

Doughty et al. (2003) also reported that 47% of the participants were single and a quarter reported being unemployed as a direct result of having epilepsy. Approximately half of the people with epilepsy felt stigmatised by their condition, although there were differences according to which country the respondents were from. Those from Spain reported lower stigma in regards to those with the condition and perceived stigma amongst people with epilepsy compared to those living in France who scored higher on the stigma scale. This difference shows that stigma is affected by where a person lives and people may be better informed about epilepsy depending on where they live. Doughty et al. (2003) concluded that people with epilepsy in Europe are generally well informed about their condition, but there are gaps in the level of knowledge in terms of causes of epilepsy and medication use.

Knowledge is central to understanding an epilepsy diagnosis and this is discussed in more depth below where studies will demonstrate that correct knowledge of epilepsy may help reduce the stigma that people with epilepsy and their families' experience. Lack of knowledge of epilepsy has been reportedly linked with stigma (Doughty et al., 2003; Tekle-Haimanot et al., 1991). A UK study of carers of people with epilepsy has found that carers possessed positive attitudes towards people with the condition and knowledge of the condition is higher amongst young educated carers (McEwan et al., 2007).

A study looking at the level of knowledge of people with and without epilepsy was carried out in secondary schools in Egypt by Shehata and Mahran (2011). Their findings showed that 92% of their participants would refuse marriage with a person with epilepsy, similar results were observed between those with epilepsy and those without the condition, while 28.4% thought that people with epilepsy should not marry. This study showed that stigma was surprisingly high across both groups. Awareness of epilepsy was 100% as all participants had either heard or read about epilepsy. They also noted that most of the students, 90% without epilepsy and 85% with epilepsy, possessed incorrect knowledge of the condition, such as causes and treatment. It appears this study also confirms that less knowledge of epilepsy would lead to more feelings of stigma concerning a person with epilepsy, even amongst those who have the condition (Shehata & Mahran, 2011).

A further study which supports the findings put forward by Shehata and Mahran (2011) is that carried out by Mecarelli et al. (2007). They also suggested that a high number of their participants, 91%, had heard about epilepsy, but had little knowledge about the condition itself. It was also shown that university students were more likely to choose correctly from the questionnaires items (Mecarelli et al., 2007). This study was limited in its exposure to participants, only upper class students and undergraduates were included from Rome which may not be representative of the general population. A study which confirms the results of Mecarelli et al. (2007) is that of Hasan et al. (2010). Their findings are in line with the findings stated above, that the Chinese population in Malaysia had heard about epilepsy but had little knowledge of the characteristics of the condition, and discrimination was observed from a minority of those taking part in the study, in regards to employment and social associations with a person with epilepsy (Hasan et al., 2010). It has been noted that higher levels of education positively affects the level of knowledge possessed about epilepsy (Doughty et al., 2003; Mecarelli et al., 2007).

A relevant study carried out in Iraqi Kurdistan, in Erbil city, consisted of 80 primary school head teachers, checking for knowledge of epilepsy and attitudes towards students with the condition (Abdulla, 2014). Knowledge was reported to be poor among the participants as over 37% stated that epilepsy was an infectious disease and 55% felt students with epilepsy should be taught in separate classes. This was paired with over 92% stating that students with epilepsy should not take part in physical exercise. The authors felt that a campaign was necessary to tackle the misinformation regarding epilepsy for better understanding of the condition and to aid management of those with epilepsy, as this can affect the quality of life of those with the condition (Abdulla, 2014).

A study carried out in Iran was inclusive of 500 participants across five major ethnicities which were of Persian, Azeri, Kurd, Lur and Arab (Masoudnia, 2009). This study showed that participants had good knowledge of epilepsy and possessed positive attitudes towards those with the condition as far as employment was concerned. Positive attitudes were also noted in regards to having their child play with another child with epilepsy but responded negatively to a close relative marrying someone with epilepsy (Masoudnia, 2009).

Demonstrating similar findings was a further study from Iran, consisting of 800 participants, which was carried out checking for knowledge and attitudes towards people with epilepsy (Ghanean, Nojomi, & Jacobsson, 2013). It was found that most people knew what epilepsy was and that it originated from the brain, although 17% stated that it was just God’s will. The majority of the participants were positive in their attitudes towards employing someone with epilepsy, having their child play with someone with the condition but again negatively responded to marriage from a member of their family with a person with the condition. People with epilepsy in

Iran felt moderately stigmatised because of their condition but less than people with mental health issues (Ghanean et al., 2013).

A study from Turkey on knowledge and attitudes towards people with epilepsy showed that even if participants were familiar with the condition, this did not necessarily help with changing negative attitudes towards those with the condition (Demirci, Dönmez, Gündoğar, & Baydar, 2007). Further discrimination emerging from the study demonstrated that some of the participants were happy to let their child play with someone with epilepsy but objected to marriage with someone with epilepsy. Lack of knowledge of epilepsy was further revealed as only 42% of participants stated that epilepsy originated from the brain. However, lack of information and discrimination was more prevalent among those belonging to older or uneducated category (Demirci et al., 2007).

A further study from Turkey looked at teachers' knowledge and attitudes towards children with asthma and epilepsy, and whether a brief educational leaflet could have a positive impact (Aydin & Yildiz, 2007). The study found that teachers had better knowledge and attitudes were more positive with those children with asthma compared to those with epilepsy. Further knowledge discrepancies showed that 30% of teachers did not want a child with epilepsy in their classroom and felt they should attend a special school; however, those with asthma were accepted to attend mainstream education. It was reported that the brief information leaflet, used for 30 days, did impact positively on knowledge and attitudes towards those with epilepsy although the effects may be temporary. The authors recommend better education to improve people's knowledge of epilepsy in order to minimise discrimination towards those with the condition (Aydin & Yildiz, 2007).

A study carried out in two counties in France by Rafael et al. (2010) also looked at knowledge of epilepsy. They reported that there were gaps in the level of knowledge participants stated, however, less knowledge of epilepsy was more common from those participants who were men, older people and those with lower education levels. They concluded their study by stating that there were misunderstandings regarding the cause of epilepsy and its treatment. Rafael et al. (2010) suggest that their study has shown a high level of stigma, and state that people with epilepsy need to be included in order to tackle the level of stigma.

Kaleyias, Tzoufi, Kotsalis, Papavasiliou, and Diamantopoulos (2005) carried out a study of teachers’ (without epilepsy) knowledge and attitudes towards epilepsy and students with epilepsy in three cities in Greece. They found that teachers have positive attitudes towards epilepsy and students with epilepsy, and most teachers felt that students should continue with their education at their normal school but have little confidence in helping a student should they experience a seizure. This shows that whilst teachers’ have positive attitudes towards students with epilepsy their knowledge is limited as far as the condition is concerned. As a direct result of their research Kaleyias et al. (2005) suggested that Greek teachers need to be provided with tools to acquire knowledge on how to help a convulsing child, should the need arise. They have also highlighted that their findings are in line with other studies carried out in Europe and accept that the society a person belongs to is a great factor in the level of knowledge and stigma regarding epilepsy and people with epilepsy (Kaleyias et al., 2005).

With societal differences come different understandings of chronic illnesses, such as epilepsy, and people’s reactions to those living with it. Research has gone to great lengths to widen our knowledge on the psychological effects of most illnesses and conditions, and it has certainly attempted to broaden our understanding of epilepsy, its characteristics and the effects on those diagnosed. However, it is unfortunate that in some countries there is a wide gap in the level of knowledge possessed by those diagnosed with epilepsy, their families and the general population (WHO, 2010).

Chapter 4: Thesis Direction and Predictions

The current chapter will outline the thesis direction, research questions and hypotheses for all studies.

A mixed methods design was adopted, using qualitative and quantitative techniques to collect and analyse data. This method was adopted mainly because, at the time of data collection, there were no existing references, to the author's knowledge, in the area of epilepsy in Kurdistan, Northern Iraq. Knowledge of illnesses and in particular epilepsy is lacking somewhat from this region of the world (WHO, 2010). Literature reported from neighbouring areas in Middle-East, such as Iran, Turkey and Saudi Arabia will be explored in relation to knowledge, attitudes, stigma and quality of life of people with epilepsy and others' perception of the condition.

This research was carried out in three parts to gain an understanding of the experiences of epilepsy and the impact of stigma on the quality of life of people with the condition. Two out of the three studies, studies one and two, explored epilepsy from the perception of those with the condition. Study three investigated the views of others (those without the condition), as the experience of stigma of someone with epilepsy is affected by the attitudes and perceptions of those without the condition (Doughty et al. 2003; Jacoby & Austin, 2007; WHO, 2010).

The first study was a qualitative investigation into the experiences of people with epilepsy. The data for this study was collected via semi-structured interviews and analysed using thematic analysis. The participants totalled 20, 10 from the UK and 10 from Kurdistan. The analysis of the first study reported the similarities as well as differences between the two groups and implications for further and future research. The second study was a quantitative study looking at the specific areas that have been found in reported literature. A total number of 172 participants, 84 from the UK and 88 from Kurdistan took part, checking for significant predictors of quality of life. Measured variables included knowledge of epilepsy, seizure severity, perceived illness seriousness, depression, perceived stigma and quality of life. The third study investigated people without epilepsy, looking at their knowledge of epilepsy and the stigma concerning those with the condition. A total number of 316 participants took part, 116 from the UK and 200 from Kurdistan, and the results were explored between the two groups checking for significance.

Chapter five will report on the first study which was the qualitative exploration of people with epilepsy. This section will not only report the results but also highlight the similarities observed between the two groups as well as the differences and what this can mean for future and further research.

Chapter six reports the quantitative study of people with epilepsy. Significance between the predictors of quality of life and correlations will be reported and analysis discussed. Comparisons between the two societies will be made and predicted hypothesis tested. The implications of the results will also be discussed in relation to further developments in this area.

Chapter seven presents the third and the last study in this thesis which concentrates on the level of knowledge of epilepsy and the stigma concerning people with the condition. This study is from the perspective of people without epilepsy. The results will be presented with the two groups in mind, the UK and Kurdistan group. Comparisons of similarities and differences will be reported and what this can mean for future developments in this area.

Chapter eight will summarise the discussions of the overall research and conclude this thesis.

The overall research aims are to understand the effects of stigma on quality of life in people with epilepsy in the UK and Kurdistan; and also looking at the knowledge of epilepsy and stigma concerning those with epilepsy from the point of view of those without the condition. This part of the study is intending to make clear how those diagnosed with epilepsy understand their condition and how they cope with their day to day lives.

Qualitative Study – People with Epilepsy – Chapter 5

Research Question	**Research Proposal**
How do people with epilepsy understand their condition in the UK and Kurdistan, and what are the impacts on their daily life?	An exploration into the lives of people with epilepsy in the UK and Kurdistan, Northern Iraq. This study will explore the possible similarities and differences between the two areas. There is no published literature in the area of Kurdistan, which was the reason that this was more of an explorative study.

Quantitative Study –People with Epilepsy – Chapter 6

Research Question	**Hypothesis**
1► Does seizure severity negatively impact on quality of life in people with epilepsy?	1► Previous literature has reported that seizure severity has a negative impact on quality of life; it is therefore hypothesised that those participants who scored high on the seizure severity scale will have scored significantly lower on the quality of life scale.
2►Does perception of illness seriousness negatively influences quality of life?	2►Those participants scoring high on the perceived illness seriousness scale will score significantly lower on the quality of life scale.
3►Do people with epilepsy living in the UK have a better quality of life compared to those living in Kurdistan,	3► Western societies are known to have a better understanding of illnesses and possess better technologies which go towards helping its members. With this

Northern Iraq?	in mind, it is hypothesised that those from the UK group will have scored significantly higher on the quality of life scale compared to the Kurdish participants.
4► Are people with epilepsy living in the UK more knowledgeable about their condition compared to those living in Kurdistan, Northern Iraq?	4►Through support groups and availability of knowledge in the UK, people may have access to more information about epilepsy and as this is not the case in Kurdistan, it is predicted that the Kurdish group will have significantly lower scores on the knowledge of epilepsy measure compared to the UK group.
5►Do people with epilepsy report more perceived stigma living in Kurdistan compared to those living in the UK?	5►According to literature, lack of knowledge in any area leads to stigma and as it is already predicted that the UK will have better knowledge of epilepsy, it is a natural progression to propose that those in the UK group will have scored significantly lower on the perceived stigma scale compared to those in the Kurdish group.
6► Do people with epilepsy living in Kurdistan report more depressive symptoms?	6► According to literature depression is associated with stigma and it is already predicted that those in the Kurdish group to perceive more stigma; it is therefore hypothesised that those in the Kurdish group to report more depressive symptoms compared to the UK group.

7► Do participants living with epilepsy in the UK report a better quality of life?	7► According to reported literature in regards to quality of life in people with epilepsy, those living in Western societies report a better quality of life compared to those in the developing countries. With this in mind, it is hypothesised that participants with epilepsy living in Kurdistan will report a significantly poorer quality of life compared to the participants with epilepsy in the UK group.

Quantitative Study – People without Epilepsy – Chapter 7

Research Question	Hypothesis
1► Does knowing someone with epilepsy have a positive effect on how much we know about the condition?	1► It is hypothesised that those who knew or had known someone with epilepsy will have significantly better knowledge of the condition.
2► Does having better knowledge of epilepsy have a positive impact on stigma in regards to people with epilepsy?	2► It is predicted that those participants with better knowledge of epilepsy will have scored significantly lower on the stigma scale.
3► Does living in Kurdistan impact on stigma views concerning people with epilepsy?	3► This may be due to the lack of awareness and knowledge of epilepsy as it is predicted that participants in the Kurdish group will have scored significantly higher on the stigma scale used compared to those in the UK group.

Chapter 5: Qualitative Study of People with Epilepsy

This chapter reports the only qualitative study in this research carried out as part of the overall investigation into epilepsy from the UK and Kurdistan, Northern Iraq. The method of analysis was Thematic. This method allows the development of themes which can then be looked at to highlight possible similarities and differences between the groups. Qualitative methods, in this case, also provided a good foundation for this research. This chapter ends with a discussion of the present study and implications for further research.

In Western societies awareness of epilepsy is on the increase with the help of better medical understanding and available support groups assisting those diagnosed with epilepsy and their families, however, this is not the case for those in the developing regions (WHO, 2010) such as Kurdish societies. In the Middle-East, epilepsy is referred to more frequently as fainting as this is seen to be less stigmatising as they are triggered by external factors and being struck by the evil eye (Good, 1994). Furthermore, the causes are sometimes associated with sins committed and those experiencing recurrent seizures are likely to attend religious healers (Good, 1994).

The research purpose of this study was to explore the lives of people with epilepsy in the UK and Kurdistan, Northern Iraq. The study was to look into: how do people with epilepsy understand their condition in the UK and Kurdistan, and what are the impacts on their daily life?

5.1. Methodology

5.1.1. Design

Research either uses qualitative or quantitative methods, or a mixture of both. Data from qualitative methods are analysed using the most appropriate method, such as thematic analysis, discourse analysis, grounded theory and narrative analysis (Smith, 2015). A definition of qualitative design is the ability for researchers to observe and interpret topics of interest in their natural environment (Ezzy, 2001; Denzin & Lincoln, 2011). Further, it allows the researcher to be flexible on the level of depth of data collection and the uniqueness of analysis (Ritchie, Lewis, Nicholls, & Ormston, 2013). Newman and Benz (1998) claim that qualitative data is where observations take place, also in the form of interviews and focus groups, in order to develop a theory whereas quantitative methods are when one starts with a hypothesis and aims to prove or disprove it.

Riessman (1993) suggests that people interpret life situations into a story, and using qualitative analysis such as narrative, allows participants to recall their story in a way that makes sense to them and reiterate important points to highlight to the researcher. The qualitative method of approach was important to use in this research as a search of the literature resulted in no publications on the experiences of people with epilepsy in Kurdistan, Iraq. It is important to get a full picture of the situation and this can only be gained by using qualitative methods. This method allows participants to share their experiences to be used as a basis for future research in this area.

Another reason for selecting a qualitative methods design is that quantitative survey based questionnaires give us statistics but fail to explain what the findings mean (Holloway & Jefferson, 2002). In order to really understand any given data, the background information is crucial and this is where a qualitative design helps the researcher (Holloway & Jefferson, 2002). In this case, due to the lack of data availability, it was essential to carry out the data collection via a qualitative method in order to be able to get a good understanding of people's perceptions of their condition. This method was also important to apply as the evidence could be used as background information in order to be able to carry out further extensive research.

5.1.2. Participants

The data includes 20 interviews from participants, 10 from the UK and 10 from Kurdistan, Northern Iraq, Sulaimania district. The inclusion criteria for this study were anyone over the age of 18 with a diagnosis of epilepsy in both regions, male or female (for more comprehensive participant information, also see Appendix 14). There was an even gender split in the Kurdish sample with five each male and female. There was an uneven split in the UK sample with 3 male and 7 female.

Table 2: Demographical Information

	Kurdistan M (SD)	**UK M (SD)**
Age- years Mean (SD)	32.1 (9.72) (range 18-44)	44.7 (16.74) (range 21-70)
Time since Diagnosis –year	10.70 (7.33) (range 2-25)	25.25 (20.39) (range 1.5-63

5.1.3.1. UK Sample Procedure

The UK participants were first approached from a personal contact and the rest were recruited using the snowball method at a conference held for epilepsy awareness which included attendees from all over the UK. The snowballing technique is essential for researchers especially when reaching a hard to access group (Breakwell, Hammond, & Fif-Schaw, 2001) such as epilepsy. Snowballing is also advantageous for accessing groups that are side-lined or stigmatised by society (Atkinson & Flint, 2001). This method allows a researcher to start off with one or more participant and is then led to other potential participants (Breakwell et al., 2001). Potential participants were approached and a brief explanation of the study was given and asked if they would take part. In this group there were no refusals to participate, however, one participant interview was excluded from the study as he did not meet the 5 year residency criteria set for all participants in the UK groups across all studies. Participants were asked for their preference on where they would like to be interviewed. 3 interviews took place in homes of participants, and the rest in a private area at the epilepsy awareness weekend conference. All efforts were made to minimise disruption during the interviews, however, disruptions were experienced during some of the interviews but these were dealt with appropriately and ensured the process was back on track without affecting the participants' privacy or disrupting the interview process.

5.1.3.2. Kurdistan Sample Procedure

With the Kurdistan participants contact was made with the Head of Psychiatry in Sulaimania and permission given to enter the hospitals and clinics for the purpose of collecting data from those with a diagnosis of epilepsy (Appendix 10.2). Those attending the hospital were from cities and villages surrounding this city hospital. A snowball technique was also used to collect data (this technique is briefly explained in the UK sample above). The researcher was allowed access to the clinic where EEGs were carried out. Potential participants were approached and asked if they would take part in the study, out of those approached only one refused as she said she did not have epilepsy. Interviews were carried out in a private room as agreed by the manager at the clinics. Some participants were referred by personal associates; these interviews were carried out in a place convenient to the participant.

5.1.3.3. General Procedure

All participants were informed prior to the interviews on the subject of the research but were not given the specific questions automatically. A printed consent form was given to the participants to read, and if happy to proceed, to sign. In all cases consent was obtained prior to the commencement of the questions and the recording of the interviews. The data from the interviews was recorded in order for it to be transcribed clearly and accurately and to be used for analysis purposes.

During the interviews, as well as the participants being prompted to expand on topics, notes were taken as recommended by Egan (2002) suggesting active listening was an important skill to exercise during interview situations. In addition, the interviews were participant-led and a naive researcher approach was adopted. Furthermore, Rogers (1994) also proposes utilising a passive stance to allow participants to self-direct without getting in the way. Before the end of the interview, all participants were asked if they wanted to add anything to the interview to bring the situation back to a neutral frame of mind.

At the end of the interview a copy of the consent form was given to participants with debriefing information and direction to get more information on epilepsy and this current research, if they wished. The researcher's contact details (email address) were highlighted to all participants if they wished to make contact at any point regarding the research.

The length of the interviews varied with the Kurdistan interviews lasting between 9:16 to 29:39 (minutes: seconds), with mean time=15:08 and the UK interviews lasting between 7:47 and 24:51, mean time=18:07 (appendix 12).

5.1.4. Ethical issues

Prior to the commencement of data collection, ethical approval was gained from Brunel University Psychology Research Ethics Committee (Appendix 10.1).

In order to help develop a rapport between the interviewer and interviewee, the participants were reassured at the beginning of the interview that the questions were not going to be intrusive and that the participants could end the discussion at any time if they wished.

5.1.5. Data collection

Qualitative research normally entails the researcher interviewing participants, usually face to face, or over the telephone or carrying out focus group analysis (Sturges & Hanrahan 2004). Interviews and focus groups are normally recorded and then transcribed, information is then analysed using the most appropriate method, in this case thematic analysis (Braun & Clarke, 2006). Semi-structured interviews were deemed the most appropriate to give participants the opportunity to share their experiences in a safe environment. Furthermore, semi-structured interviews allow participants to elaborate on factors that affect them in their daily lives which can result in getting the most data for analysis.

Data was collected by semi-structured interviews directly from participants. By using semi-structured interviews, the rigidness of questionnaires and surveys can be avoided as well as allowing more flexibility for the researcher to explore relevant topics as they emerge from the participants and for the participant to be able to elaborate on issues of importance (Smith, Harre, & Langenhove, 1995).

5.1.6. Interview Schedule

The line of questioning had to be appropriate across the UK and Kurdish participants as there was an element of the unknown as far as the Kurdish society was concerned due to the scarcity of research in this area. The interview schedule was developed following a review of the research that has previously been reported in the developed and some from the developing regions on the experiences of people with epilepsy. Questions had to be sensitive to the religious and cultural differences as values may differ between the two samples. The questions were open ended to allow participants to elaborate on their topics of interest. Questions such as ‘‘Tell me the circumstances around your diagnosis’’ and ‘‘How did you feel when you were first diagnosed?’’ were used. For this study, the interview schedule consisted of around 30 questions which were used as a guide during the interviews; a digital voice recorder was used to record the sessions and headphones to transcribe the data.

The content of the questions were split into 3 parts (Appendix 10.3). The first section was on demographics, including age, occupation, and how long they had been diagnosed with epilepsy. In this section, the questions were quite generic to put the participants at ease and to build a trusting rapport between the interviewer and the participants. The second part was on diagnosis and their lives since their diagnosis of epilepsy, and availability of support from their families, friends and external organisations. The third section dealt with the types of support systems that participants felt worked better having to deal with an epilepsy diagnosis. Questions regarding the societal acceptance of epilepsy were also enquired about, along with the type of advice they would give to a newly diagnosed person with epilepsy.

The interview schedule was first written and approved by supervisors in English for the UK group and translated into Kurdish following correct guidelines of translation procedures by a native Kurdish speaker who was fluent in English for the Kurdish group (Vîlceanu, 2008). The guidelines available for translations are that the original text to be translated from the original language, which was English, into the chosen language, in this case Kurdish, has to be by a native speaker who is fluent in English. The interview schedule was then back translated following the same guidelines (Vîlceanu, 2008) in order to ensure that meaning was not lost according to published literature in this field (Cramer et al., 1998).

5.1.7. Data Analysis

Thematic analysis was used to analyse all interviews, this is a method where data is coded and themes are drawn from the data. Thematic analysis is the process by which themes are developed from data obtained from qualitative data collection such as interviews and focus groups (Braun & Clarke, 2006). This technique also allows for theme identification and sometimes, to be compared between groups (Clarke, Davies, Jenney, Glaser, & Eiser, 2005). This procedure allows for individual as well as group traits to emerge and be accounted for (Ely, Vinz, Downing, & Anzul, 1997; Braun & Clarke, 2006). Braun and Clarke (2006) explain that thematic analysis is one of the foundations for qualitative research, and that one of its many benefits is that it's flexible.

All the interviews that were conducted in Kurdistan were then transcribed in Kurdish then translated into English for analysis by the author. The UK interviews were transcribed precisely and all the data was thematically analysed as described (Ely et al., 1997; Braun & Clarke, 2006) using the ten step system. This method of analysis is systematic and allows the researcher to follow guidelines as to not rush the procedure to allow for theme development as a gradual process (Braun & Clarke, 2006).

The procedure of thematic analysis was used to analyse the data (Ely et al., 1997): step (1) was to read and re-read all raw data which was the transcribed interviews; (2) then writing down first ideas from each segment of the data on one side of the text; (3) making notes of provisional groupings on the other side of the text; (4) then going over steps 2 and 3 to filter groups; (5) categorising the data under the provisional groups which are formed as a result of steps 1-5; (6) the process is then to find precise links within the data of association within the transcribed texts; (7) then reading the outcome of step 6 and amend if needed; (8) then stating themes that have emerged from each participant and finding associations within and across groups; (9) incorporating the results from each participant; and finally (10) assessing all the results for any patterns and distinction. This procedure was followed for each participant’s data to ensure consistency and accuracy of the analysis used.

5.1.8. Reflexivity

Reflexivity is a chance for a researcher to acknowledge their own position in research and how human factors may influence responses from participants. It is impossible to eliminate all researcher influences; however, it is important to be aware of one’s own position in research (Nightingale & Cromby, 1999).

Reflexivity entails that awareness from the researcher is essential to the contribution of producing meaning throughout the process of research, and also to understand the impracticality of complete objectivity in terms of the topic of study (Nightingale & Cromby, 1999).

Reflexivity further demands acknowledgements of the researcher's own personal and professional reasons behind their choice of subject (Nightingale & Cromby, 1999). Here, the researcher’s motive for choosing the topic was brought on by her own interest in the research field and lack of available sources. Furthermore, being female and from a Kurdish background was evident to participants, especially in the Kurdish group as the spoken language was shared. Although, no obvious effects were noted, it is impossible to know the impact of these factors on the outcome of the research. As a result, the researcher was mindful to take note of these human and other contributory factors, which may influence the process of data collection and analysis.

5.2. Results

Table 3, below, presents the main themes and sub-themes extracted from the interviews conducted in the UK and Kurdistan. The themes present a picture of the experience of living with Epilepsy. Differences as well as similarities were observed within and between the two groups.

The groups (the UK and Kurdistan) in this study were comparable in that all participants were diagnosed with epilepsy and over the age of 18. However, there were also differences in age and length of diagnosis. The age range for the participants from the UK group were 21 to 70, with a mean age of *M*= 49, whilst the Kurdish participants were aged 18 to 44, with a mean age of *M*= 26. The length of diagnosis was 1.5 to 63 years for the UK participants and 2 to 25 years for the participants in the Kurdish group. It is a possibility that the difference in the age range and length of diagnosis between the two groups could reflect the maximum age amongst the Kurdish participants due to the type of sampling used in this study (see chapter five, sub-section 5.1.3.1, pages 66-67).

Table 3: Themes and Sub-themes Extracted from Data

Main Themes	Sub-themes
1. Living with Epilepsy	*1.1. Diagnosis* *1.2. Seizures*
2. Impact of Living with Epilepsy	*2.1. Loss of Independence & Restrictions* *2.2. Lack of Control*
3. Adjustment	*3.1. Causal Beliefs of Epilepsy* *3.2. Acceptance*
4. Coping	*4.1. Illness Comparison* *4.2. Support*
5. Stigma	*5.1. Concealment/Disclosure of Diagnosis* *5.2. Experience/Perception of Stigma*

5.2.1. Theme 1. Living with Epilepsy

This theme has highlighted the experiences of those living with epilepsy in the UK and Kurdistan. Whilst there may be differences in how people with epilepsy live with their condition, the results have highlighted observations of common characteristics, these are in the form of sub-themes which include Diagnosis and Seizures.

5.2.1.1. Sub-theme 1.1: Diagnosis

Participants reported a variety of emotions associated with the diagnosis of epilepsy. Societal differences between the two groups were also evident. Most of the UK participants and half of the Kurdistan participants were included in this sub theme, nevertheless, the difference was very striking. Those from the UK group reported of the shock and disbelief of receiving the diagnosis and some wanted a second opinion. However, the Kurdistan participants almost appeared helpless and reported that they accepted the diagnosis of their epilepsy without question as it was '*God*' given. Furthermore, the participants reported that they had no emotions associated with being diagnosed with epilepsy at all. Those who were diagnosed from an early age were too young to associate particular feelings to the diagnosis and only recognised the effects of their epilepsy once they were older and could understand what the condition meant for them, this was true across both groups.

The first statement is from a participant from the UK group. The passage below shows the participant's reaction to her diagnosis, which was initially denial, shock and disbelief and the demanding of a second opinion. This shows that the participants did not just accept the diagnosis, as did the Kurdish participants, but shows they wanted to be in control of their diagnosis and not the epilepsy.

''I was in shock, I was like 'no you're wrong, do something else, do another', and I changed hospitals, I went to another, (Hospital 1), and the guy said, same diagnosis, I said 'no', 'well no' he said, he agreed.'' (UK participant 8, page 8, lines 94-97)

The Kurdish participant's reaction, however, appeared to show no emotion when being diagnosed with epilepsy, but rather simply accepted the condition as '*God given*'. It is difficult to speculate on the reactions given by the Kurdish participants, some may be genuinely accepting of their condition because of their religious beliefs. However, some may be reacting this way because they are in denial due to the social restrictions a diagnosis of epilepsy imposes and the level of stigma which is present in their society.

''I had no feelings, I said you know, its God given, sometimes God gives us illnesses.'' (Kurdistan participant 3, page 2, lines 54-55)

5.2.1.2. Sub-theme 1.2: Seizures

This sub-theme appeared in both groups as seizures were part of the everyday life of those with epilepsy and stress was a major trigger, more so for the UK participants than Kurdistan participants. Eight of the ten UK participant mentioned stress as a seizure trigger while only three Kurdistan participants found stress to be a trigger for an epileptic seizure. Seven Kurdish participants were unsure of the triggers of their seizures. Perhaps there was a lack of knowledge about epilepsy as a condition in the Kurdish group which may have meant that less attention was given to the triggers of the condition.

The UK participant below made the observation that associated her seizures with environmental circumstances that she perceived as traumatic. The participant described her dealing with a traumatic event when visiting family which she believed caused her seizures to return after a considerable period of seizure freedom. This analysis puts the stressors of the return of her symptoms down to external factors, which were outside of her control.

''I do think the biggest trigger have been stress and it's not the everyday stress you know these little things, but something a bit more substantial like what you carry constantly, [.... ....] they can be quite erratic sometimes and recently when I've been seizure free for a year or so I had a traumatic event and after I returned home I had two weeks of constant aura so we realised how easily they can return and so it seems that trauma in my life can bring it on.'' (UK participant 5, page 4, lines 116-128)

Comments from the UK participant above show how '*substantial*' stress brought about her seizures, not the daily struggles, for example, public transport or being annoyed by someone, but deeper issues possibly relating to family and the support system. In contrast, the Kurdish participants showed how the accumulation of many small stressful events, such as socialising and undertaking everyday chores, can bring about tiredness and stress which in turn can bring about a seizure. The passage below, from the Kurdistan participant, shows that most of the causes of her seizures were put down to physical exhaustion, and others down to external stressors. It also appears that the Kurdish participant was in constant anticipation of her seizures by associating most of her daily activities to experiencing a seizure.

Stress was responsible on a number of occasions from participants from both groups as one of the biggest causes for seizure reoccurrence and some felt they had to restrict themselves on how much they could do and sometimes even give up some activities to avoid exhaustion.

‘‘For me it’s a lot … if I have a headache I will have a seizure, if I stress about the smallest things, if someone says the smallest thing to me I get like that (experience a seizure), so if I am at a party and I get tired, or walking and I get tired, or when I do housework, just housework I get tired and I get like that.’’ (Kurdistan participant 7, page 3, lines 65-69)

The UK participants were knowledgeable that not adhering to medication and leading an unhealthy lifestyle can act as a trigger for their seizures, as well as causes that are beyond the control of the individual, such as flashing lights, and other external factors. The UK participants appeared to be more in tune with the causes of their seizures compared to those in the Kurdistan group, as is shown in the quote below.

‘‘Yeah, stress is a very big one, err obviously not taking pills, err tiredness, erm dehydration and flashing lights as well but not in the normal sense, a lot of epileptics they have flashing lights but I have strobe lights affect but strobe lights don’t affect me, if it were to be a normal light like it would be flashing on and off, constant, constant ray then that would affect me.’’ (UK participant 7, page 2, lines 57-63)

5.2.2. Theme 2: Impact of Living with Epilepsy

A diagnosis of epilepsy affects those with the condition, and this theme shows the extent to which people with epilepsy feel they are restricted in their daily life. The UK group appeared more knowledgeable about their diagnosis of epilepsy and made a conscious decision to try and maintain as much of their daily activities as their conditions allowed. Nevertheless, they were also more in tune with the activities they may no longer be able to carry out. In this theme there are two sub-themes which are (2.1) Loss of Independence & Restrictions; and (2.2) Lack of Control, they are discussed below.

5.2.2.1. Sub-theme 2.1: Loss of Independence & Restrictions

Most of the participants from both groups recognised the restrictions they faced as a direct result of epilepsy and the diagnosis, which they felt affected their life. This sub-theme was common to both groups; however, there was a difference. Whilst the UK participants felt they were more restricted in practical tasks such as driving and swimming, the Kurdish participants felt they lost their social standing in the community and that their marriage prospects and social activities were affected.

The restrictions experienced by a participant from the UK centred on participating in life with regards to work and social activities. The loss of a driving license is common with people with epilepsy in the UK, which can impose restrictions. The suddenness with which it occurs means that the ability to participate socially and as a productive member of society is restricted. This meant that participants had no option but to accept and adapt very quickly.

''At 23, I was working, I was driving, suddenly find that I lose my driving license err, [……] Err you know, working, driving, socialising it was more sort of you know, what sort of impact was it having on my life?'' (UK participant 4, page 2, lines 42-50)

The Kurdish participant below felt defined by the physical and social restrictions she experienced as a result of her condition. The social differences are very clear in this instance as for the UK participant it was more the loss of independence of the individual that is relevant and the practical activities that are limited, such as driving and career choice. For the Kurdish participant, however, it was more the effects a diagnosis has on the restrictions on social identity in the community and its effects on the family. It appears from the analysis that the participant felt the experience of seizures and a diagnosis of epilepsy affected her life negatively. The effects of epilepsy is that, in this case, the participant no longer wants to go out in case she has a seizure which is having a negative influence on her being part of her society.

"Sometimes, if I wanted to go somewhere, to travel, if I got ill health, if I wanted to go somewhere, for a picnic, for a visit, to go out, if I got ill health I couldn't go even if I had got changed, I changed back saying 'it's better I don't go', most of the time I've gone and on the way I got it (seizure), those things are really upsetting."(Kurdistan participant 8, page 5, lines 139-144)

5.2.2.2. Sub-theme 2.2: Lack of Control

A big issue for people with epilepsy in both groups was the perceived lack of control with regards to the unpredictable nature of seizures. Most of the participants in the UK group and some of the participants in the Kurdistan group described how they felt restricted in their everyday life due to this lack of control. The '*not knowing'* shows the unpredictable nature of epilepsy and when a seizure will next occur was a concern. The UK participant below stated that she would be happy to make compromises in order to help make the seizures stop or know when a seizure will happen next. This lack of control was an issue for most people with epilepsy.

''I think the not knowing (when seizures occur), and you don't, not knowing how to control it either, [……..]which would be nice to know what contributes and I think not knowing and also just having one, it's like 'what did just happen?'' (UK participant 8, pages 8-9, lines 289-299)

The Kurdish participant below was referring to the dangers associated with the unpredictability of his seizures. He highlighted that the lack of control over the seizures he had experienced were not only upsetting but also very dangerous.

''It was very upsetting because that illness, whether you say it or not it's a bad illness, I mean you get it suddenly, you could fall in fire, a lot of times, sometimes I've even burnt, I would be standing up unaware then suddenly fall on stone or fire I've fallen on it. I mean those instances have been very upsetting.'' (Kurdistan participant 8, page 2, lines 33-38)

Lack of control was highlighted a number of times in both groups as a restriction on daily activities. Epilepsy is not a clear cut condition and it is difficult for physicians to prescribe the activities to avoid, as there are so many different types of seizures and triggers and this appears to be a very individual condition.

5.2.3. Theme 3: Adjustment

This theme shows the differences in approaches to the diagnosis of epilepsy. There are two sub-themes in this main theme, (3.1) Causal beliefs of Epilepsy; and (3.2) Acceptance. It is important to understand how a person diagnosed with epilepsy can adjust to the condition.

5.2.3.1. Sub theme 3.1: Causal Beliefs of Epilepsy

In order for participants to adjust to their condition, they felt a need to understand the reasons for how they came to have epilepsy. Some of the UK participants and most of the Kurdish participants gave some reasons for their diagnosis. The UK group had received information regarding the reasons for their condition from their doctors, such as a mother's drinking whilst pregnant; one participant said 'simply, meningitis'; and lack of oxygen when they were born was given by another. On the other hand, the Kurdish participants had less of an opinion as to what caused their epilepsy, the main cause of their diagnosis was believed to be associated with stress and trauma and one believed epilepsy had a genetic predisposition.

For one UK participant below, the possible root of the cause of her epilepsy diagnosis had been explained to her by her doctors and this information appears to have helped her adjust to her condition. Having an explanation of the cause for this participant also eliminated personal responsibility of having a diagnosis of epilepsy and through the extent of the explanation given to her by the medical profession has helped her deal with her symptoms more effectively.

‘‘Erm, my mother drank a lot when she was pregnant with me and the doctors have said that that’s what probably has caused the scarring on my brain, which has caused the epilepsy, so [… ….] nothing I can do about it so I’m just going to have to carry on taking the medication and get on with it.’’ (UK participant 1, page 5, lines 138-145)

The Kurdish participant below shows how the trauma of losing her brother when he was 12 may have contributed to the cause of her epilepsy. The diagnosis and the onset of epilepsy are singularly attributed to an emotional trauma that was experienced. The disappointment of false hope given to her by the medical professionals that the condition was temporary was clear.

‘‘I had an accident, I mean my brother got run over by a car, he was 12 years old, I got it from that, when I got it I went to the doctors a lot, they kept telling me you’ll get better.’’ (Kurdistan participant 8, page 1, lines 22-24)

The Kurdish participant below attributes that the cause of his epilepsy was ‘*God*’ given and he had no other explanations.

‘‘This is something that God has given me, each person has a different illness, and is in agony with a different pain, but my pain is different to all the others pains.’’ (Kurdistan participant 5, page 4, lines 114-117)

There is a difference in causal beliefs about epilepsy between the two groups; some participants from the UK were more informed regarding the causes of epilepsy in comparison to those in the Kurdistan group. Stress and trauma was one of the explanations given from participants from both groups, more so in the Kurdish group than the UK. More of the UK participants associated causes of epilepsy to physical abnormalities and explanations, whilst most of the Kurdish participants associated the causes of epilepsy to psychological traumas.

5.2.3.2. Sub-theme 3.2: Acceptance

This sub-theme was also one of the categories where there was a difference between how those in the UK and Kurdistan group accepted their condition. Most of the UK participants accepted their epilepsy and would be quite clear that people diagnosed with epilepsy should strive to learn about their condition. However, most of the Kurdish participants were hoping for a cure rather than learning about their condition, and rationalised the diagnosis in a spiritual manner, usually mentioning the word '*God*' in their acceptance of their condition. Acceptance was because one had '*no choice'* but to accept the condition and they were hoping '*God*' would take the illness away from them.

The UK participant below acknowledges her epilepsy and that she has seizures, but it appears that she has no problems in accepting it as part of her life. The unpredictable seizures do not appear to affect her in a negative way as she continues with her life in a 'normal' way.

''It's not that I think that I have nothing wrong but I sort of thought its part of my life, I have seizures and continue with my life and that's about it, just part of, have a seizure continue with life, that's erm, [… ….] there was this fuss around you which was unnecessary but it happened.'' (UK participant 5, page 2, lines 60-67)

Acceptance amongst the participants in the Kurdistan group was through spiritual means. The Kurdish participant below accepted his epilepsy but felt that he was waiting for '*God*' to help him. The locus of control has been given to an external power source, '*God*', and he hoped that '*God*' took away his condition. It also shows that there is a certain feeling of helplessness attached to those in the Kurdistan group. They have been summoned with this condition, '*God*' has bestowed onto them, almost like a gift and they have no power or control over what happens. It is almost like a special condition, that it is said to be a '*different kind of pain'* or illness.

''Well mentally, I got happy with God and said 'God I'm depending on you, I've now got this I have to tolerate it', until God sends me protection, I have to be in charge of myself, be happy with myself and I can't let it get to me so I don't get worse, and get

other illnesses, I tried to control it rather than the illness controlling me.'' (Kurdistan participant 8, page 4, lines 122-127)

Spirituality appears to affect how a Kurdish person with epilepsy accepts a diagnosis of epilepsy and how they manage their condition. Acceptance of epilepsy by the person diagnosed appears to be more consistent with the UK participants than those from the Kurdish group. The UK group were more aware of the symptoms of their condition and how to best help themselves, for example, ensuring they were not too physically stressed and medication was adhered to, in contrast, participants in the Kurdish group were not as informed about their epilepsy.

The statements from the Kurdish group generally appear that even with the presence of religion, accepting epilepsy was very difficult and their pleas were mainly to ask '*God*' to take away their illness showing that accepting an epilepsy diagnosis was difficult for those in the Kurdistan group.

''I would like a cure for this illness, a lasting cure that even those who get like that (have epilepsy) to be cured.'' (Kurdistan participant 5, page 5, lines 155-156)

''I say 'God please take this illness away from me and I don't want anything else from the great God.'' (Kurdistan participant 6, page 7, lines 223-225)

5.2.4. Theme 4: Coping with Epilepsy

Coping with a chronic condition such as epilepsy presents its challenges for those with the condition. This theme highlighted the factors that influence how people with epilepsy cope with their condition. This theme consisted of two sub-themes, (4.1.) Illness Comparison and; (4.2.) Support.

5.2.4.1. Sub-theme 4.1: Illness Comparison

A pattern where participants compared themselves to others which helped them to accept their condition better was apparent in the data. This comparison was uniform across both groups; however, it was more prevalent with the Kurdish group. Some of the UK participants compared their condition to other disabilities whilst most of the Kurdish participants used their epilepsy and compared with others with the same condition but with different symptoms to aid their acceptance.

The UK participant below used downward positive comparison and compared himself to someone worse off than him and felt better about his own condition as a result. He appeared to explain that not all types of epilepsy are bad, that '*you don't always fall to the ground*'. This participant further explained that a diagnosis of epilepsy was not the worst thing to happen, and compared his own epilepsy to those with physical disabilities, and felt that these were much worse than having epilepsy.

''I mean there's so many seizures, you don't always fall to the ground and hurt yourself, you could have other types of seizure [… ….] but don't feel sorry for yourself, because there's always somebody else worse off, erm, when if you watched the Olympic games, the Paralympics, all the people that have got sort of amputated limbs, I mean that's far worse, that is.'' (UK participant 10, pages 8-9, lines 277-286)

The Kurdish participant also used social comparison with someone worse off than him to make himself feel better as a result. This social and illness comparison happened in both groups, more so amongst the Kurdish participants than those from the UK.

''Sometimes I try and make myself feel better, I see someone disabled, blind or in a wheelchair, I make myself feel better, I talk to myself and say 'look how he is, at least you walk with your own feet and your eyes are fine' I make myself feel better with that.'' (Kurdistan participant 2, page 8, lines 237-241)

5.2.4.2. Sub-theme 4.2: Support

This sub-theme showed a great difference between the participants from the UK and Kurdistan. The UK participants were comforted to know that they were surrounded by friends and family whilst they were having a seizure as they felt they received emotional support. The Kurdish participants reported being content with the physical or practical support they received from those around them, rather than the emotional support. This included having their arms and legs held down, having a tissue inserted into their mouths to prevent injuries to their tongue, and having their eyes closed and foreheads held. There was a belief amongst the Kurdish participants that these actions can bring a person round from having an epileptic seizure.

The UK participant below described the reassurance he felt having his mother present during his seizure, providing him with feelings of security whilst in a vulnerable state. This type of comment was made by many other UK participants showing that the importance of support lay in emotional rather than the physical approach.

''Ohh, well she was always just concerned that I was alright or one thing or another, when I immediately come round I was sort of, sort of too groggy and sort of out of it to sort of care, err it was that I knew mum was there and it was nice to know that your mum was there if you know what I mean, if you're not feeling well.'' (UK participant 4, page 6, lines 186-191)

The Kurdish participant below described the help she received from her husband whilst she experienced a seizure, and although by European standards it is very dangerous to put anything in the mouth of someone during this state, she felt comforted that he put a ball of tissues in her mouth to stop her from biting, and this appears to be the support that she felt she needed. This sub-theme showed a great difference between the groups, as to how to support someone with epilepsy; this may also be due to the different expectations of support from family and friends which may be due to societal differences.

''But now my husband takes lots of tissue and put it in my mouth so I don't bite, of course he was very good to me. It was lately that he discovered how to do it, err, then you have to hold on, I don't know how, he says you froth at the mouth.'' (Kurdistan participant 1, page 9, lines 274-279)

5.2.5. Theme 5: Stigma

With a diagnosis of epilepsy come the perception and the experience of stigma, which can lead to emotional and psychological consequences. This theme shows the variety of changes that a person diagnosed with epilepsy goes through in order to still be able to function in a 'normal' society. This theme has provided two sub-themes, (5.1) Concealment/Disclosure of Diagnosis and; (5.2) Experience/Perception of Stigma.

5.2.5.1. Sub-theme 5.1: Concealment/Disclosure of Diagnosis

There was a difference between the UK and the Kurdistan groups in this sub-theme, whilst the UK participants reported they were happy to share their condition with those around them, perhaps for support, especially if they were to spend more time with them, most of the Kurdistan participants would not disclose their epilepsy diagnosis, sometimes even after experiencing a seizure in front of others.

This participant from the UK group felt comfortable for others to know of her condition and was happy to disclose to those around her. This was the case for most of the participants in the UK group, especially if they were to spend more time in others' company, so they were aware in case they experienced a seizure. The UK participant below shows that there appeared to be no hesitation about informing those around her to know of her condition. And no thought is given to hiding her condition at all.

''Well everybody who knows me now knows, there wouldn't be anybody who, and my medication is right out on display, my alarm goes off for me to take my medication so if I'm out with people in the evening my alarm will go off at 9 o'clock and everybody knows I would take my medication erm, …'' (UK participant 2, page 7, lines 213-218)

This Kurdish participant (below) had epilepsy for some years but had only disclosed to one of his friends and was adamant that he did not want anyone else to know but he could not explain the reason, just simply that he did not want them to know. He later said that epilepsy is a bad word and people use it in a demeaning way. The way he explained his condition to his friend is almost as if he was ashamed to have epilepsy and perhaps the society he inhabits influenced this young person to associate his condition as a mark of shame.

‘‘I had one friend and we came to the hospital at lunch time, we finished school and I said ‘come on, let’s go’ he said ‘what is it?’ I said ‘come on, let’s go and pick these medications’ he said ‘why?’ I said ‘it’s for this sort of illness’ I told him ‘I haven’t spoken about it to anyone and you don’t talk about it to anyone’.’’ (Kurdistan participant 5, page 5, lines 137-142)

When prompted further regarding his epilepsy and who may know about it he stated:

‘‘No, even with the relatives, the ones who may have found out is two of my uncles and one of my aunts, and my other uncles and other aunts don’t know.’’ (Kurdistan participant 5, page 6, lines 160-162)

When asked why his response was:

‘‘Because I don’t want them to know, I don’t want them to.’’ (Kurdistan participant 5, page 6, lines 164-165)

There is a very clear distinction between how a person in the UK deals with their epilepsy diagnosis compared to that in Kurdistan. Most of the UK participants see epilepsy as just another condition that needs awareness and medication and those in the Kurdistan group appeared to see it more as something to be hidden and did not want others to know.

5.2.5.2. Sub-theme 5.2: Experience/Perception of Stigma

This sub-theme invoked quite a lot of emotions in both groups, the UK and Kurdistan; however, the type of stigma they felt appeared to be different. While those in the UK reported feeling stigmatised because associations were made as a result of their age, from being young and mistaken for a drunk whilst having a seizure on the street, to being older and being mistaken for a recovering alcoholic. The Kurdish participants felt mocked by others because of their condition and being made fun of because of their seizures. The stigma felt in the Kurdish group did not appear to be age relevant as it was in the UK group.

The statement below was from a 21 year old female from the UK group explaining how she felt judged because of her epilepsy and her age. Although this quote could also support the lack of support she receives when she has a seizure, the point she was making in the interview was that people were making assumptions of intoxication due to her age rather than epilepsy.

''I don't think a lot of people know about it, I think because I'm an adult now, everybody thinks I'm drunk or been drinking, that's why I'm collapsed on the street, [.... ....] sometimes I have to go to hospital and a lot of people don't even come up to me to check if I'm alright or ask 'are you ok?' they just walk past me thinking I'm one of those adults whose addicted to alcohol or something.'' (UK participant 9, page 5, lines 138-149)

The participant below from the Kurdistan group explains how she felt stigmatised by her work colleagues because of her epilepsy and how it affected her. The participant below is describing how her colleagues would talk about their other colleague who had epilepsy, but as the participant had epilepsy herself she took this personally. The idea of mocking is very obvious from the way the participant described her feelings of the need to conceal her condition. This participant said that although she had not been confronted with it, she was aware of the undercurrent stigma, which unsettled her. It almost sounds like her work colleagues were accusing her other colleague of purposely having a seizure, that the individual had control over the seizures and can somehow bring it on themselves.

''No one has told me face to face, but that lady who had epilepsy she wasn't at work,[... ...] her husband wanted to remarry, not because that woman is bad, he just said he liked to have two wives, they would all say 'why shouldn't he remarry, 12 months in a year he has to take care of this woman until she comes to', seriously

those talks are very hurtful. It’s true she wasn’t there but I have feeling, it’s hurtful. It’s very difficult.’’ (Kurdistan participant 4, pages 8-9, lines 282-291)

The Kurdistan participant below is associating having epilepsy to the anticipated stigma that may follow. He is describing having epilepsy as a ‘discrediting’ factor to himself and worries that people will discredit him as a result of his condition. The Kurdish participant is also describing *felt* stigma. The personal shame attached to having a condition such as epilepsy.

‘‘It’s just nice, it’s nice for people to have a healthy body and with people appears to have a healthy body not fall among people and have seizures, and soon people will say, and if they see you anywhere they look at you differently because that’s how it is in our country.’’ (Kurdistan participant 2, page 5, lines 137-141)

5.3. Discussion

This research was carried out to understand the experience of living with epilepsy from two different societies. Five main themes developed from the data which were (1) Living with Epilepsy; (2) Impact of Living with Epilepsy; (3) Adjustment; (4) Coping and; (5) Stigma, each with two sub-themes.

The first theme, (1) Living with Epilepsy, and sub-themes included (1.1) Diagnosis and; (1.2) Seizures. The first sub-theme, (1.1) Diagnosis was noted to be different for both groups. A diagnosis of epilepsy affects every part of a person's life and the changes are very sudden (WHO, 2010; ILAE, 2014). Whilst those in the UK sample strived to understand, and in some cases get a second opinion, those in the Kurdish group were accepting of their condition without hesitation. Kurdish participants rationalised their epilepsy diagnosis in a spiritual manner, usually mentioning the word 'God'. This type of acceptance of diagnosis affected their behaviour in a way they appeared to have been defeated until 'God' took away the condition from them. This may due to the religious beliefs held in that culture or how serious they feel their condition was; this is in line with studies that indicate that religious and spiritual beliefs help with accepting an epilepsy diagnosis (Ismail et al., 2005). This study confirms that religious beliefs may have contributed to the acceptance epilepsy amongst the Kurdish society.

The second sub-theme, (1.2) Seizures are one of the symptoms of epilepsy that many people with the condition struggle with and has been linked with poor quality of life (Guekht et al., 2007). The UK participants ensured that they were aware of the causes that may increase seizure frequency, such as avoiding their triggers; however, this was not apparent from the Kurdistan group. Stress was mentioned as affecting seizure across both groups but more so in the UK group than those in the Kurdish group, the majority of the Kurdish participants stated that they were unsure of the causes that brought on their seizure. It is suggested that seizure freedom is necessary for improvements to be observed in quality of life of people with epilepsy (Birbeck, Hays, Cui, & Vickrey, 2002).

The second main theme was, (2) Impact of Living with Epilepsy and consisted of two sub-themes. In the first sub-theme, (2.1) Loss of Independence & Restrictions, a clear difference was noted in that while the UK participants felt they were more restricted in practical tasks such as driving (Jacoby & Austin, 2007) and swimming, the Kurdish participants felt they lost their social standing in the community and that their marriage prospects and social activities were affected (Jacoby et al., 2008). Participants from both groups recognised the restrictions they encountered as a direct result of epilepsy and their diagnosis, which they felt affected their life. This resonates with the suggestion of the direct and indirect effects of epilepsy, as proposed by Bishop and Allen (2003). It appears that the Kurdish participants refer to the indirect effects of epilepsy, while the UK participants raised the direct effects as being the main factor in its effects. The second sub-theme, (2.2) Lack of Control, was shown to be consistent with both groups and the uncontrollability and the not knowing when a seizure occurs was a problem for those with epilepsy. No social differences were noted here between the two groups as the lack of control of seizures affected all people with epilepsy, as previously noted (Devillis et al., 1980; Velissaris et al., 2007; Mikulincer, 2013).

The third main theme was, (3) Adjustment and consisted of two sub-themes. Participants from both groups wanted to understand the cause of their condition (3.1) Causal Beliefs of Epilepsy. Some of the participants from both groups suggested reasons for their condition. However, whilst the UK group based their beliefs about the cause of their epilepsy on medical advice given to them (Angus-Leppan, 2008) those in the Kurdish group mostly put the condition down to stress and trauma, possibly due to the unavailability of technologies for an in-depth diagnosis (Birbeck, 2010). It is a possibility that by the UK participants having medical advice about the cause of their epilepsy could help better adjust to their condition, as it has been suggested that better knowledge leads to better adjustment as shown in people with diabetes (Jerant, Friederichs-Fitzwater, & Moore, 2005). Stress and trauma were highlighted by a number of participants from the Kurdistan group as a cause of an epilepsy diagnosis and continued seizure episodes, this may explain the high numbers of diagnosis in the developing countries which has been claimed (WHO, 2010). Although, stress was mentioned more by the UK participants as a trigger rather than a cause compared to the Kurdish participants, who associated stress as the main cause of a diagnosis. Participants in the Kurdish group did not have the available literature or resources in order to be able to understand the individual causes of epilepsy, such as scarring and head trauma which can be given through further tests using MRI and CAT scans, which are not available in this area of the developing countries (Birbeck, 2010).

The (3.2) Acceptance sub-theme was very different between the two groups. The UK participants were able to ask questions of their doctors and find information regarding their condition, however, the Kurdish participants accepted their condition because it was from 'God' and did not enquire or investigate further. In this research, participants who were less resourceful tended to feel they had no control over their epilepsy (Rosenbaum, 1984), in this case those in the Kurdish group. However, the participants from the UK group were more proactive in getting information regarding their condition. There was a very clear cut distinction between the two groups and this requires further investigation. Regardless of acceptance, having a diagnosis of epilepsy affects a person's life, the effects will depend on how much restriction is imposed on the person (WHO, 2010).

Some aspects of this research finding were in line with other reported studies concerning acceptance of an epilepsy diagnosis as reported by Mirnics et al. (2001) which proposed that the role of family is very important in accepting and coping with a diagnosis of epilepsy, this was shown in the present study across both UK and Kurdish groups. However, because of the societal structure, the Kurdish participants were much more reliant on spiritual and religious beliefs to accept their diagnosis and help with coping with their condition as seen in other studies (Ismail et al., 2005).

Gourie-Devi et al. (2010) stated that having religious beliefs may help people with epilepsy manage their condition and feel they have control over their condition. Although with the UK participants, religion and spiritual beliefs did not play a part in how they accepted their epilepsy diagnosis. Those in the Kurdish group, however, relied heavily on their religious and spiritual beliefs to explain their diagnosis, but this did not necessarily mean better seizure management and control of their symptoms. Previously, religious beliefs have been associated with less symptom severity and better quality of life in cancer patients. However, it was reported that general well-being overrides religious or spiritual well-being when looking at quality of life (Laubmeier, Zakowski, & Bair, 2004). Spiritual beliefs tended to help the participants in the Kurdish group see epilepsy as a ‘gift from God’ and that there was no choice in whether they accepted it or not, nevertheless, this did not equate to better coping or quality of life.

The fourth main theme was (4) Coping with two sub-themes. The first sub-theme, (4.1) Illness Comparison, was shown to be consistent across both groups, although more prevalent within the Kurdish participants. The UK participants made comparisons with different disabilities whilst the Kurdistan participants made comparisons within different symptoms of epilepsy as well as other illnesses. It has been found that illness comparison has been positively correlated with self-esteem and negatively correlated with depressions (Dagnan & Sandhu, 1999). Coping with epilepsy is an important factor in people with the condition as it can have a detrimental effect on the quality of life (Kumari et al., 2009).

The second sub-theme, (4.2) Support, showed a difference in the type of support a person received during a seizure. The Kurdish participants wanted support to be more physical, such as holding down their arms and legs, closing their eyes and holding their forehead in the hope that the person experiencing the seizure to come around out of their episode. It has to be noted that many decades ago advice from the medical professionals in Western societies may not have been too different, but as it stands today, with the amount of knowledge surrounding neurological conditions this is not the case (Temkin, 1994). In contrast, the UK participants were happy with emotional support, such as knowing someone was present when they experienced a seizure. The difference may be due to the fact that the two groups differ socially or the misconceptions that are held by those with epilepsy (Kumari et al., 2009) impact on the type of support they require. People with epilepsy are more aware of the ‘dos’ and ‘don’ts’ of the condition in the Western societies and it appears as though modern information on epilepsy has not travelled to these parts of the world as yet

(WHO, 2010). This may be due to the lack of research in the developing countries, and especially the Kurdish region of Iraq due to political instability (Meho & Maglaughlin, 2001).

The fifth main theme, (5) Stigma consisted of two sub-themes. The first sub-theme (5.1) Concealment/Disclosure of Diagnosis, showed a difference between the comments made by the participants from the two groups on whether those with epilepsy disclosed their condition or not. In the Kurdish group, participants reported not wanting to disclose their condition, and were proactive in its concealment; this may be fuelled by the perception that due to the misconceptions of society others may want to stay away from them (Kleck et al., 1968). This anticipation of stigma associated with misconceptions could persuade those with epilepsy to conceal their condition (Kleck, et al., 1968; Schnieder & Conrad, 1980; Joachim & Acorn, 2000).

An individual's identity, in any given society, is created differently depending on where people live in the world, as the person is shaped by the experiences and expectations of their environment (Goffman, 1969). The concept of being 'discredited' for having epilepsy is apparent from the results (Goffman, 1963). It appears that, although the UK participants reported being stigmatised because of their epilepsy, they were not completely devalued as members of society. Amongst the Kurdish participants, however, the fear of being looked down upon and not being treated as a 'normal' in their society impacted on whether they disclosed their condition or not. As the perception of 'normal' is maintained, the individuals with epilepsy can still be credible members of their society (Goffman, 1963). Amongst the Kurdish participant, in order to continue being 'credible' or valued members of their society, the decision was taken to conceal their condition. For the Kurdish person with epilepsy, it is not only about the career they would be denied, but also being a counted and respected member of their society. Maintaining normality in society, also protects others (family and friends) being associated to a stigmatising condition, where associations between the credible and the discredited are 'spoiled interactions' (Goffman, 1963).

Those in the UK group, however, appeared more able to disclose freely, usually as they felt it in their best interest, especially if they were to spend more time with those around them. It may be that the participants in the UK group felt that the environment was accepting of their condition which encouraged ‘coming out’ (Schnieder & Conrad, 1980). Different beliefs about epilepsy or simply the lack of knowledge available to people may also affect whether people can disclose or conceal their condition. The members of the UK society are free from social restrictions and familial obligations which could take away the negative impacts concerning stigmatising conditions from others in society (Kashima et al., 1995).

The second sub-theme, (5.2) Experience/Perception of Stigma in epilepsy has been highly reported and is widespread in all societies and that there is a great need to further understand this phenomenon, especially in the Middle-East region (WHO, 2010). Descriptions of felt and enacted stigma were seen among the UK participants (Scambler & Hopkins, 1990; Scambler, 1993; Jacoby & Austin, 2007). One participant in particular from the UK group described what is known as institutionalised stigma as suggested by Jacoby and Austin (2007), where he felt that his previous employer had not taken the type of epilepsy he had into consideration and so this had made him conceal his epilepsy from his current employer. The anticipation of stigma affects peoples’ decision as to whether epilepsy remains a secret condition or it is disclosed (Schnieder & Conrad, 1980). It is evident from the results that a person with epilepsy in the Kurdistan group felt pressured to keep their diagnosis hidden and, possibly, it was the anticipated stigma which aided the concealment of their epilepsy (Kleck, et al., 1968; Schnieder & Conrad, 1980 and; Joachim & Acorn, 2000).

This research has shown that there are differences between the impacts of society on how people understand their epilepsy. It is important to highlight that where a person with epilepsy lives has an effect on stigma and perceived stigma and ultimately quality of life (Tekle-Haimanot et al., 1991; Doughty et al., 2003; WHO, 2010; Shehata & Mahran, 2011; Abdulla, 2014). The way a person with epilepsy goes about their daily life is affected by how that particular society view their condition and this can sometimes change the course of a person’s life (Fernandes et al., 2008;

WHO, 2010; Ahmad, 2011). For example, in the UK sample having a diagnosis of epilepsy would mean legislative restrictions, such as a driving ban and career choice (Jacoby & Austin, 2007), for the Kurdish group it would mean whether a person has a place in society and social settings (Jacoby et al., 2008; Hosseini et al., 2010).

This study was not theory driven; however, the results do support existing theories in this area. These results are in support of the *Hidden Distress Model,* suggesting there are different types of stigma experienced by the participants in the study; these are *felt* and *enacted* stigma (Scrambler, 1989). This model explains that certain characteristics about a person would cause others to have negative attitudes towards the person with the stigmatising condition or characteristics. It appears that the UK participants reported more on the *enacted* stigma whilst with the Kurdish participants it was *felt* stigma that was highlighted the most. Katz (1981) suggested that there is a distinction between a stigma that is known and one that is hidden from knowledge. In this research it appeared that the difference was quite clear, the type of stigma reported by the UK participants were different to that experienced by the Kurdish participants. Different types of stigma, *felt*, *enacted*, *institutional* and *individual,* were reported by participants across the two groups, however, *felt* stigma was reported mainly by the participants in the Kurdish group, and evidence of *enacted* and *institutionalised* stigma was reported mainly by the UK participants. The concept of *felt* and *enacted* stigma is very similar in its reference to the direct and indirect effects of epilepsy (Bishop & Allen, 2003). The direct effects of epilepsy would be *enacted* stigma, and the indirect effects would be *felt* stigma. This study has shown support for both these theories where the UK report the direct effects and the Kurdish participants report the indirect effects of epilepsy.

This research has uncovered information where the Kurdish society is concerned and also the different types of stigma present in both the UK and Kurdistan groups. The current findings are in line with the study reported by Fernandes et al. (2004) stating that stigma is a result of lack of knowledge and this can sometimes be concurrent with offensive behaviour. This was observed amongst participants in the Kurdish group who reported the term ‘epilepsy’ was associated with demeaning character or behaviour. It appears that stigma in the Kurdish culture is also teamed with offensive or disrespectful behaviour, as previously proposed (Fernandes et al., 2004). The UK participants, however, experienced stigma in the way that they felt *institutionally* and *individually* stigmatised (Jacoby & Austin, 2007), for example, a young girl's seizure being associated with a drunken behaviour because of her age.

As mentioned above, where a person lives in the world affects others' perception of epilepsy, and the stigma they have about the condition (Fernandes et al. 2008). This is where the society that individuals live can play a role in how some conditions are viewed and whether or not the illness or condition is acceptable to that culture. In the UK people are more independent and are expected to count in society individually and prefer to be left alone to be getting on with things (Kashima et al., 1995; Veenhoven, 1999). The Kurdish society, however, is more about family, community and tradition, and the role a person plays in a family very much affects others' perception and the role of family in that society (Meho & Maglaughlin, 2001). Family and the community play a greater part in an individual's life in the Kurdish culture (Meho & Maglaughlin, 2001). This difference in society could also be suggestive of the effect of epilepsy on a person with the condition. In the UK, the effect of epilepsy could be associated with the individual with the condition and it may not negatively affect others in the family. However, the effect of epilepsy on a Kurdish person could have a ripple effect on the family and their place in their community.

The results of this study are in line with some aspects of other reported studies; however, as this study was unique in that there is no reported literature in this area of Middle-East to the author's knowledge, it is unclear how the results of this study will be utilised. These findings, once published, will find be a good foundation in the available literature and contribute to knowledge in this area of research. In conclusion, this study has found that seizures impact greatly on people with epilepsy and that disclosure is possible with a supportive environment. This study has also found that the concept of spirituality may require additional investigations to highlight its effects on accepting a chronic condition, such as epilepsy, and whether spiritual beliefs in Kurdistan can help with better management of the condition. Furthermore, it has been found previously that social support has been linked to better illness management (Gallant, 2003); however, social support does not appear to be available for those with epilepsy in Kurdistan. Further findings include the types of stigma present in the UK and Kurdistan, which appear to impact the lives of people with epilepsy and their families.

The findings of this study have highlighted that psychosocial issues, such as adjustment, coping and stigma are factors associated with a diagnosis of epilepsy. Stigma has been one of the main themes that have emerged and appears to be different depending on the group the participants were from. Furthermore, stigma has been previously found to affect quality of life (Jacoby, 2002; Whatley et al., 2010; Ahmad, 2011), and this will be further explored in the next study where predictors of quality of life in people with epilepsy will be investigated.

This study was not without its limitations, whilst the UK participants were happy to elaborate during the interviews; the Kurdish participants were less forward in their role in the study. As the Kurdish culture is restrictive to individuals and other people’s perceptions are very important, generally there are restrictions on whether they are able to disclose their condition and whether they can talk freely. For this purpose the interviews conducted in the Kurdish group were almost always shorter in time compared to the UK interviews.

Another limitation to this study was that some of the participants in the Kurdish group were uncomfortable talking about their condition which resulted in a restricted data collection. Participants in the Kurdistan group did not always want to elaborate on issues surrounding epilepsy or their coping mechanism. Also, to bring the interview to a more positive state of mind, it was posed to the participants the question of their future hopes and dreams, this was met with much dissatisfaction and defensiveness and answered with statements like ‘of course I have hopes and dreams, just like anyone else’. This was at the beginning of the data collection for the qualitative study, and the decision was made not to end on that note, instead it was decided to let the interviews come to a natural close. Nevertheless, this study was essential for the progress of knowledge of epilepsy in this area of the developing countries and also in the UK.

Chapter 6: Quantitative Study of People with Epilepsy

This chapter presents the first quantitative study, the study of people with epilepsy in the UK and Kurdistan. The purpose of this investigation was to explore the predictors of quality of life of people with epilepsy. This chapter will present the method section, followed by the results. The results will be analysed for all the participants in the study collectively. The participants will then be separated by group (the UK and Kurdistan) checking for shared similarities as well as differences. This chapter will end by discussing the findings in relation to published literature and recommendations for further research.

Knowledge of epilepsy is more advanced in Western Societies and an awareness of the factors affecting a person with the condition, which impacts on the quality of life of people with epilepsy, is better known compared to those in the developing countries (WHO, 2010). Research in the area of epilepsy in people with the condition in the developing regions is limited in its availability (WHO, 2010) especially in Kurdistan, Northern Iraq highlighting the need for further research.

The results from the previous study (chapter 5) showed that the participants were affected by their epilepsy. Stigma, one of the main themes in the previous chapter, has been previously associated with quality of life (Jacoby, 2002; Whatley et al., 2010; Ahmad, 2011). In chapter five, it was also clear that there was a difference between the types of stigma participants reported depending on the group they belonged to (the UK and Kurdistan). Stigma has been previously associated with lack of knowledge in some societies (WHO, 2010). Furthermore, stigma appears to depend on where in the world a person with epilepsy lives (Fernandes et al., 2004). The present study will aim to compliment the previous study (chapter five), in that it will look at the difference in the two societies in relation to the knowledge held by the participants, the stigma they report and whether this affects their quality of life. Other factors, such as seizure severity, perceived illness seriousness and depression will also be considered.

The overall purpose of this research is to explore perceived stigma people with epilepsy report and how this impact on their quality of life, and whether this experience is different for those living in the UK compared to those living in the Kurdistan region.

The hypotheses that will be tested in this chapter will be:

1. Based on previous literature, it is expected that seizure severity has a negative impact on quality of life; it is therefore hypothesised that participants in this study who scored high on the seizure severity scale will have reported significantly poorer quality of life.

2. It is predicted that participants in this study scoring high on the perceived illness seriousness scale will have reported significantly poorer quality of life.

3. It is hypothesised that the participants in this study from the UK group will have reported significantly better quality of life compared to the participants in the Kurdish group.

4. It is predicted that the Kurdish group will have significantly lower scores on the knowledge of epilepsy measure compared to the UK group.

5. Those in the UK group will have scored significantly lower on the perceived stigma scale compared to those in the Kurdish group.

6. It is predicted that the UK group will have scored significantly lower on the depression scale compared to the Kurdish group.

7. It is hypothesised that participants with epilepsy living in Kurdistan will report a significantly poorer quality of life compared to the participants with epilepsy in the UK group.

6.1. Methods Section

6.1.1. Design

A statistically measurable design was used to test the hypotheses in this study and to measure the relationship between the predictor variables and quality of life. This type of design looks at the response from a group of individuals identifying similar trends and tests for significance in relationships (Yaremko, 1986). Additionally, a quantitative design is theory driven, meaning that the hypotheses were based on reported literature in this area of research (Creswell, 2013). Furthermore, a quantitative methods design is an objective method of collecting data from a large group (Creswell, 2009, 2013).

6.1.2. Participants

The participants in the Kurdish group were recruited from Neurology clinics (state and private), pharmacies (as patients came in to fill their prescriptions for their epilepsy medications) and some from personal contacts. Questionnaires were only accessible in paper format due to the limited availability and access to technology. The UK participants were recruited from the Epilepsy Action weekend conferences, parents from primary schools and Brunel University notice boards. Kurdistan participants were all born and living in Kurdistan; the UK participants were controlled for a minimum of 5 years residence in the UK to be eligible to participate, however, out of 84 participants 74 were born in the UK. Other inclusion criteria were that participants were over the age of 18 and had been diagnosed with epilepsy.

6.1.3. Ethical Issues

Ethical approval was received from Brunel University Psychology Research Ethics Committee (see also chapter 5, section 5.1.7, and Appendix 10.1) and from the Neurology Hospital in Sulaimania (Appendix 10.2).

6.1.4. Measures

The variables measured were age, gender, knowledge of epilepsy, perceived illness seriousness, depression, seizure severity, perceived stigma and quality of life. The questionnaires used in the study were the same in the UK and Kurdistan groups; however, those used in the Kurdistan group were translated into Kurdish, Sorani dialect. To ensure reliability of the translated items, the Kurdish text was then back translated (Brislin, 1970, Harkness, Van de Vijver, & Mohler, 2003) into English to confirm meaning was not lost. A native Kurdish speaker translated the measures and items into Kurdish and was back translated by another native speaker from Kurdish to English. This process was carried out for the entire questionnaire as a whole, including instructions and demographic information. The process adopted in this study is also reported by Cramer et al. (1998) for translation and back translating of the QOLIE-31.

All questionnaires started with ‘‘Hello, thank you for agreeing to take part in this questionnaire. The following questions are about you, please answer as truthfully as you can. There is no right or wrong answer, I am only interested in your views.’’ The demographic section, then followed which asked for information including age (measured continuously), gender, occupation, highest educational qualification, country/town of birth, country/town of residence (if different from birth), time at place of residence, ‘‘Have you been diagnosed with epilepsy?’’, and ‘‘When were you diagnosed with epilepsy?’’. Some of these were open text where participants could add their own information, and for other questions options were given for selection (see Appendix 10.9). The next section was the Knowledge of Epilepsy (Doughty et al., 2003), then Seizure Severity scale (Scott-Lennox, Bryant-Comstock, Lennox, Lennox, & Baker, 2001), Perceived Stigma (King et al., 2007), Brief Illness Seriousness Perception (Broadbent, Petrie, Main, & Weinman, 2006) Depression scale (Radloff, 1977) and Quality of Life (Cramer, Perrine, Devinsky, & Meador, 1996).

6.1.4.1. Knowledge of Epilepsy

The Epilepsy Knowledge Questionnaire (EKG) by Doughty et al. (2003) was the first measure used after the demographics section and contained 34 items. The items, for example, ask questions about the medical characteristics of epilepsy. This measure contained 19 true statements and 15 false statements. The participants were given instructions before the start of this section and read ‘‘The following statements contain information about epilepsy, please decide whether you think the statement is TRUE or FALSE and tick accordingly.’’ Each item was a statement. For example, the first item stated: ‘‘Epilepsy is always caused by brain damage’’, and the choice to be selected by participants was either ‘‘True’’ or ‘‘False’’. In this case the correct answer is ‘‘False’’ so participants who ticked ‘‘True’’ were given a score of ‘0’ and for those who ticked ‘‘False’’ were given a score of ‘1’. The rating scale used in SPSS was Nominal for this measure as the answers were True/False, which were computed as ‘0’ for incorerect answers and ‘1’ for correct responses. In total, there were 32 missing items between all participants. As there were no instructions from the authors as to how to deal with missing data, the decisions was taken to insert ‘0’ for each missing item in SPSS. The answers were then calculated by adding all the correct answers to reach a final score, and this figure was then used for further analysis. The higher participants scored in this measure the better the knowledge of epilepsy.

6.1.4.2.Epilepsy Seizure Severity

The Liverpool Seizure Severity Scale 2.0 (Scott-Lennox et al., 2001) was used to measure seizure severity which was the second measure to be used in this study. The internal reliability using Cronbach’s alpha was between α = 0.66-0.87. The instructions given were ‘‘The following questions are on how often you experience symptoms of epilepsy. Please read the following questions and tick on the scale where it is most true for you.’’ and ‘‘Please complete the following questions thinking about the most severe seizure you experienced during the past 4 weeks.’’ The first two items inquired about how often the participants experienced seizures, and the second item asked how many seizures they had experienced in the past 4 weeks, if they had not experienced any seizures, they would be required to put ‘0’ in the space provided. The next 12 items were asking participants to state how long it would take for them to recover after a seizure. For example, item 12 stated ‘‘After my most severe seizures I can normally return to what I am doing in:’’ and the options for participant choice were ‘Less than 1 minute’, ‘Between 1 and 5 minutes’, ‘Between 6 minutes and 1 hour’, ‘1 to 2 hours’ and ‘More than 2 hours’. Participants had between four to six options to choose from for each item. From the measure, items 1, 3, 4, 6, 7, 8, 9 10 and 11 were reverse coded on SPSS so that higher values reflect more seizure severity. From items 3-14, if the response from participants had 4 or more missing items, they were to be assigned a missing score. If the missing responses were between 1-3 missed items, according to the instructions given by the authors, an average of the non-missing responses from 3-14 was to be used for the missing items. The rating scale used in SPSS was Interval for this measure and responses from participants were computed, from 1-5 or 6, according to the indications made by the participants depending on the item. In total there were 23 missing items from the questionnaires which were calculated using the procedure above. The data were then calculated by using the scoring instructions from the authors and further analysis was carried using SPSS. After reverse coding, the calculations were to add the responses from 3-14 ⁄ 40 × 100, to give a score ranging from 0-100.

6.1.4.3.Perceived Stigma

Perceived Stigma (King et al 2007) was the third section of the questionnaire and contained 28 items. Cronbach’s alpha was used to measure the internal consistency which was $\alpha = 0.87$. In this study the reliability for this measure using Cronbach’s alpha is α=.80, for the UK group α=.88, and the Kurdistan group α=.45 but increases to α=.533 with the deletion of item 23. Instructions to participants were ‘‘Please read the following statements and tick on the scale where you feel you most agree/disagree with the statement.’’ For example, item five read ‘‘I worry about telling people I receive epilepsy treatment’’ and the options for participants were ‘Strongly agree’, ‘Agree’, ‘Neither agree nor disagree’, Disagree’, and ‘Strongly disagree’ and were required to pick one of the given preferences. From this measure items 3, 4, 7, 10, 14, 15, 19, 23 and 24 were reverse coded in SPSS as those items reflected a positive view rather than stigma. The rating scale for this measure was interval and computed into SPSS from 1-5, depending on participants responses. There were 23 missing items from the participant responses overall. As there were no instructions from the authors, after reverse coding, the missing items were given a score of ‘0’. The data were calculated by adding the scores from each item to reach a final score. In this scale higher scores indicated higher levels of perceived stigma.

6.1.4.4.Illness Seriousness Perception

Brief Illness Seriousness Perception (Broadbent et al., 2006) was the fourth section in this study. Reliability was checked using test-retest at 3 and 6 week intervals which is reported between r=0.42–0.75. Instructions given to participants were ‘‘The following questions are on the how epilepsy has affected your life. Please circle the number that best corresponds to your views:’’, which was for items one to eight, an example of item one was ‘‘How does your epilepsy affect your life?’’ and the options available were ‘‘No affect at all’’ to ‘‘Severely affects my life’’ with scoring from ‘0’ to ‘10’. With items measuring consequences, timeline (how long the participant thinks they will have epilepsy), control over epilepsy, control over epilepsy with medication, symptoms of epilepsy, concern over their epilepsy, participants’ understanding of their epilepsy, and the emotional experiences of epilepsy (Broadbend et al., 2006). Item nine required participants to state the cause of their epilepsy and were asked to rank in order of importance, the instruction for this item was ‘‘Please list in rank-order the three most important factors that you believe caused your epilepsy,’’ ‘‘The most important causes for me: -’’ and were given three lines to write what they thought caused their epilepsy. All preferences were listed from all participants and qualitatively analysed using content analysis (Hsieh & Shannon, 2005) and put into categories that was then put into SPSS as categorical data for analysis. Scores for items 1-8 were calculated using the value selected by each participant for each item, the higher the score the more serious participants felt about their condition. The rating scale used was interval and computed in SPSS using scores from 1-5. There were no missing items from the responses the participants had indicated on the questionnaires.

6.1.4.5.Depressive Symptoms

The CES-D Scale for depression (Radloff, 1977) was the fifth section and contained 20 items. The reliability of this measure was reported using test-retest method at 2, 4, 6, and 8 week intervals, and is reported between r=0.51-0.67. The instructions given to participants at the start of this measure were ‘‘Below is a list of ways you might have felt or behaved. Please tell me how often you have felt this way during the past week.’’ The participants were given a list of statements such as (item one) ‘‘I was bothered by things that usually don’t bother me’’ and asked to make a selection from ‘Rarely or none of the time (less than 1 day)’, ‘Some or little of the time (1-2 days)’, ‘Occasionally or moderate amount of time (3-4 days)’ and ‘Most or all of the time (5-7 days)’. Items 4, 8, 12 and 16 in the measure were reverse coded as they represented a more positive view of how the participants have felt about themselves. After reverse coding, the scores were added and a higher total score indicated more depressive symptoms. The rating scale used in this measure was interval and computed in SPSS using scores from 1-4 depending on the responses from the participants. In total there were 15 missing items from the overall participant responses. There were no instructions from the author as to how to deal with missing data, in this case, after reverse coding, the missing items were given a value of ‘0’.

6.1.4.6.Quality of Life

Quality of Life (Cramer et al., 1996) or QOLIE-10-P (Quality of Life in Epilepsy) which is derived from QOLIE-89 (Devinsky et al., 1995) and QOLIE-31 (Cramer et al., 1998; Cramer et al., 2000). This was the sixth and final measure in the questionnaire and contained 12 items. This measure covered three areas, (1) the effects of epilepsy which included memory, the physical effects and the mental effects of medication, (2) mental health which measured for energy, depression, and overall quality of life and (3) role functioning which included seizure worry, working, driving and social capacity (Cramer et al, 1996).

There are many measures specifically looking into the quality of life in people with epilepsy such as the Liverpool Quality of Life Battery (Baker, Smith, Dewey, Jacoby, & Chadwick, 1993). This measure looks into the overall quality of life in people with epilepsy and includes physical, social and psychological aspects; however, an overall score for quality of life is not achieved but rather separate scores for a series of questionnaires (Baker et al., 1993; Cramer, 2002). An overall score for quality of life was necessary in order to look for relationships between the measures in the study. The internal consistency using Cronbach's alpha is α=0.69-0.85 (Baker et al., 1993). Another instrument is the Quality of Life Assessment Schedule (QOLAS) used for rating quality of life in people with epilepsy. This measure requires detailed interviews with participants and the rating is carried out by a trained individual (Kendrick & Trimble, 1992). These measures can be quite lengthy and time consuming as one consists of a series of questionnaires (Liverpool Quality of life Battery) and the other detailed interviews with participants (QOLAS) (Cramer, 2002). These measures would not have been suitable in this study due to the possibility that longer questionnaires could lead to high attrition rates and not being able to look for significant relationships between all the measures, which includes quality of life.

Another measure is the Quality of life in Epilepsy-89 (QOLIE-89) tool which is a comprehensive assessment of quality of life in people with epilepsy, containing 89 items (Devinsky et al., 1995). The internal consistency of this measure has been reported to be between α=0.78-0.92. This is the longer version which takes around 30 minutes to complete (Cramer, 2002). A shorter version of the QOLIE-89 is the Quality of life in Epilepsy-31 (QOLIE-31) (Cramer, Arrigo, Van Hammée, & Bromfield, 2000). This is a 31 item questionnaire and takes 10 minutes to complete (Cramer, 2002). The internal consistency using Cronbach's alpha is between α= 0.77-0.85, and reliability between r=0.64-0.085 (Cramer, et al., 2000). Longer questionnaires were not considered to avoid high attrition rates and the suitability of the content of the measures, the decision was made to choose a questionnaire which considers factors associated with epilepsy, such as mental, physical and medical aspects, but is also a shorter version. The Quality of Life in Epilepsy-10 (QOLIE-10) (Cramer et al., 1996) measures factors associated with a diagnosis of epilepsy, such as psychological, physical and medical influences, and can be completed in 3-5 minutes (Cramer, 2002). The sub-scales in the QOLIE- 31 and QOLIE-10 have shown to correlate at an acceptable level, r=0.54-0.73 (Cramer et al., 1996). Furthermore, using the test-retest for reliability, the figures reported were between r=0.48-0.81 (Cramer et al., 2000).

In a report it has been shown that although the QOLIE-10 is a shorter version of the original questionnaire (QOLIE-89) and it was initially devised for screening purposes, it is a reliable measure when time and resources are limited and it can be used in research (Cramer et al., 2000). Furthermore, the results of this report have shown that the outcome of the QOLIE-31 and QOLIE-10 are similar (Cramer et al., 2000). Measures' checking for quality of life in epilepsy has to be valid and reliable, as well as simple and brief (Baker, 2001), which the QOLIE-10 has shown to be.

Researching any concept developed in one society has difficulties being implemented in another due to the relevance and meaning held by its members. Quality of life is not a concept that has been looked at as yet in a society such as Kurdistan, Northern Iraq. This is mainly due to the delays in research development in the society. The quality of life measure, in the majority of cases (around 90%), was carried out in person to give the participants the opportunity to ask questions regarding any items that were not clear, however; questions were not raised at any time by the participants during data collection. In circumstances where the participants took the questionnaire home to be sent or brought back, they were provided with contact details in cases of any questions or queries, there were no issues raised in regards to the quality of life measure as a whole or items separately. It appears that the concept of quality of life was understood, so the assumption is that the concepts were relevant and fit for purpose in this study.

The instructions given to participants in this section were ''The following questions ask about how epilepsy has affected your life. These questions are about how you have been FEELING and the type of problems you have been having during the past **4 weeks**. For each question, please give the one answer that comes closest to the way you have been feeling.'' An example of one of the items is ''How much does the state of your epilepsy-related quality of life distress you overall?'' and the options give were 'Not at all, ', Somewhat', 'Moderately', 'A lot' and 'Very much' and were given numbers from 1-5, 1 being 'Not at all' to 5 representing 'Very much'. Items 1, 4, 5, 6, 7, 8, 10 and 11 were reverse coded to ensure higher scores represented better quality of life. After reverse coding the items as stated above, the scores were added to make a total score, and the higher scores signify better quality of life. Interval rating scale was used in SPSS and computed using scores from 1-5 depending on the participant responses. There were 18 missing items between all the participants. There were no instrcutions from the authors on how to deal with missing data, in this case after reverse coding, the missing items were given a score of ‘0’.

6.1.5.1. UK Sample Procedure

Information regarding this study was put on a poster and left at Brunel University informing potential participants of the study and how they could take part; instructing them to an online access of the questionnaire. Details of the study were also printed on leaflets and business cards which were given out to people attending an epilepsy awareness weekend conference held in London. Attendees were from all over the UK. Questionnaires were made available via an online format on Survey Monkey for the UK group, as well as paper format for those attending the epilepsy awareness weakened. Data collection continued for about 2 years to ensure a considerable number of participants were recruited. Some participants, teachers and parents of children, were recruited from schools in West London, for which paper copies were provided as well as information regarding electronic access. For the UK group a total of 28 questionnaires were filled out electronically and 56 in paper format.

The online details were sent out to all personal contacts and asked if they would be happy to participate in the study and also asked to circulate to anyone who may be interested in taking part. Social media, such as Facebook and LinkedIn, were also used to circulate the details of the study to raise awareness of this research. Other potential participants were approached and asked if they would complete a questionnaire on epilepsy, if they were happy to take part, those who agreed were given the questionnaire of which the consent form was highlighted to read and sign. All participants were required to sign a consent form prior to starting the questionnaire and on the online form, it was ticked to show consent, if this was not marked the participants would not be able to continue. Once the participants were happy they were asked to read all the questions carefully and ensure all sections were completed.

6.1.5.2. Kurdistan Sample Procedure

For those in the Kurdistan group only paper copies were made available due to the unavailability of electronic software. Questionnaires were taken to the Neurology clinics (state and private) in Sulaimania and pharmacies where prescriptions were filled out.

6.1.5.3. General Procedure

A few participants (n=3) in the UK and some (n=35) participants in Kurdistan wanted help with filling in the questionnaires, either due to illiteracy or general lack of understanding as to how to fill in questionnaires, those who requested help were read the questions and asked for their selection which was then made for them. If the participants were illiterate, their names and date would be written by the researcher but a form of signature was placed by the participants where this was requested on the consent form. The online questionnaire's first page was the consent form of which participants had to tick to show they are happy to continue with the questionnaire and the rest of the form was electronically carried out by the participants at their convenience, after the demographics section any items that were not completed the system would not allow participants to continue, this measure was put in place to ensure forms were filled out completely, 18 forms that were not completely filled in were disregarded. The rest of the UK and Kurdish groups recorded their selections on paper forms. If large chunks of the questionnaires were missed they were not counted and sometimes those participants who had given contact details were contacted to ask them regarding any missed items and most replied and provided the choices they would put on the questionnaire. There were two participants in the UK group who were contacted to complete their questionnaires by email. There were 18 incomplete questionnaires from the Kurdish group which were not used as the opportunity to approach the participants was not available. Participants who preferred to take the form home were provided with a stamped and addressed envelope. There were 100 paper copies made for the UK group, two were posted back incomplete (as mentioned above), three were posted back not completed at all and 39 were not returned. For the Kurdish group 120 paper copies were made, 18 (as mentioned above) were incomplete and not used and 14 were not returned. All participants were provided with a debrief form. All participants were thanked for their participation and given an email contact in case they had further queries, which was available on the consent and debrief form.

At the end of the questionnaire participants were thanked for their time and for taking part in the research and given an option whether they would like to participate in further research, if they ticked yes, then they were required to leave contact details which were name, telephone number and email address. Survey Monkey participants were unable to go back to questions once they had left the page and were also unable to proceed unless they made one selection from each item, this was mainly to ensure a reduction in missing or incomplete data.

6.1.6. Data Analysis

All data collected via questionnaires were put into SPSS. Accuracy was checked at interval stages of the data entry by checking and re-checking the data. Further checks were made by using SPSS where frequencies were examined to ensure correction of data entry and the reliability of the measures were also inspected. The skewness, kurtosis and Cronbach's alpha (α) reported the overall description of the measures used, however, detailed information for each item on the measures were also noted (Appendices 11.1-11.11). The reliability of the Knowedge of Epilepsy measure in this study is reported using Cronbach's alph. All participants together, α=.80, the UK group α=.47, and the Kurdistan group α=.07. The Cronbach's alpha for Seizure Severity is α=.37, but increases to α=.53 with the deletion of item seven. The reliability for the UK group is α=.30, but increases to α=.51 by deleting item seven, and the Kurdistan group α=.45 and can increase to α=.58 by deleting item seven. For Perceived Illness Seriousness the reliability as measured by Cronbach's alpha is α=.57 for all participants, α=.72 for the UK group and α=.44 for the Kurdistan group but can increase to α=.50 by deleting item seven. For the Depression Scale reliability using Cronbach’s alpha is α=.90 overall, for the UK group α=.91 and for the Kurdistan group α=.90 is observed. The reliability for Quality of Life for the whole group is α=.83, for the UK group α=.85 and α=.80 for the Kurdish group.

Both skewness and kurtosis assumes normal distribution at 0, anything above or below 0 is not considered normal (Tabachnik & Fidell, 2007). However, distribution can range from -1 to +1 (Hair, Black, Babin, Anderson, & Tatham, 2006), although, it is also acceptable to be more lenient and set the skewness and kurtosis level ranging between 3 to -3 (Crawshaw & Chambers, 2002).

For the knowledge of epilepsy measure skewness=.051 and Kurtosis=-1.394, seizure severity had skewness=.029 and kurtosis=-.691, perceived illness seriousness had skewness=-.159 and kurtosis=-.037, perceived stigma had skewness=-.471 and kurtosis=.418, depression had skewness=.473 and kurtosis=-.441 and quality of life had skewness =.035 and kurtosis =-.746. All the measures used in this study had skewness and kurtosis of normal distribution. Each item in the measures used was also checked for its normality and distribution (appendix 11.1-11.9). Scores for all measures were calculated using the authors scoring manuals and the data from participants from the UK and Kurdistan were analysed using Hierarchical Multiple Linear Regression.

When it came to analysing the data, all efforts were made to ensure that the data up to that point was accurate and complied with the rules of the analyses used. It is generally understood that Regression or parametric analysis can be very sensitive to outliers and can affect data outcome (Tabachnik & Fidell, 2007). From the tests that were run, it came to light that from the Perceived Stigma measure participants 152, 90, 138 and 163 were recognised as outliers for having either very low or very high scores. Bearing in mind that the mean score for this measure was mean= 52.88, the scores for these items were participant 152 got a total score of 17 for perceived stigma, participant 90 had a total of 19 and participant 138 scored 21. The next outlier came from the Perceived Illness Seriousness questionnaire, in which participant number 127 scored 15, which was quite low compared to the mean=

47.44. All questionnaires showing up as having an outlier score were checked manually and the data entered into SPSS, it was clear that the outliers were not anomalies and were the correct participant responses. The decision was made to leave the outliers as they were as they were true participant response (Field, 2005). Other ways of dealing with outliers were explored such as using the mean scores, however, this seemed to bring out new outliers after each editing of the scores (Field, 2005).

6.2. Results

For the study of people with epilepsy the predictor variables used to forecast quality of life were knowledge of epilepsy, seizure severity, perceived illness seriousness, perceived stigma and depressive symptoms.

6.2.1. Participant Characteristics

A total of 172 participants were included in this study of which 88 were Kurdish participants and 84 were UK participants. Further socio-demographic characteristics of the participants in this study are shown in table 4

Table 4: Socio-demographic characteristics for all participants from the UK and Kurdistan groups

	UK		Total	Kurdish		Total	Significance
	n	%	n (%)	n	%	n (%)	
Gender							
Male	27	32.1%	84	40	45.5%	88	.03
Female	55	67.9%	(100%)	48	54.5%	(100%)	.07
Marital Status							
Single	39	46.4%		34	38.6%		.01
Married	32	38.1%		45	51.1%		.04
Divorced	8	9.5%		1	1.1%		.01
Widowed	2	2.4%		–	–		
Living with Partner	2	2.4%		–	–		
Separated	1	1.2%		–	–		
Missing	–	–		8	9.1%		
Occupation							
Student	3	3.6%		8	9.1%		.07
Teacher/Lecturer	3	3.6%		3	3.4%		.47
Office Worker	11	13.1%		–	–		
Civil Servant	1	1.2%		11	12.5%		.00
Housewife/Husband	–	–		25	28.4%		
Unemployed	8	9.5%		14	15.9%		.10
Other	32	38.1%		19	21.6%		.01
Missing	26	31%		8	9.1%		.00
Education							
Illiterate	1	1.2%		17	19.3%		.00
Primary School	1	1.2%		22	25.3%		.00
Secondary School	26	31%		38	43.2%		.05
Diploma	14	16.7%		4	4.5%		.00
Undergraduate	22	26.5%		6	6.8%		.00

Postgraduate	11	13.1%	–	–	
Missing	9	10.7%	1	1.1%	.00
Diagnosis Period (years)					
0-5	10	11.9%	23	26.1%	.00
6-10	11	13.1%	19	21.6%	.07
11-20	14	16.7%	22	25%	.08
20 +	44	52.4%	19	21.6%	.00
Missing	5	6%	5	5.7%	.46

The mean (*M*), standard deviation (*SD*) and range are reported in table (5). The descriptive statistics show that there is a large variance between the participant scores, especially perceived stigma and quality of life measures. Furthermore, it indicates that the scores vary across all measures which suggest the variety of different scores reported by participants in the study as whole in regards to the different measures used.

Table 5: The descriptive statistics for the measures used reporting the mean, SD and range of the whole group, UK and Kurdistan together

Variables	**Mean (SD)**	**Range (min-max)**
Knowledge of Epilepsy	22.86 (5.47)	20 (13-33)
Seizure Severity	51.12 (12.05)	60 (17.50-75)
Perceived Illness Seriousness	47.44 (12.98)	65 (15-80)
Stigma	52.88 (12.79)	74 (17-91)
Depression	22.45 (12.95)	55.73 (0-55.73
Quality of Life	50.10 (21.79)	95.91 (0-95.91

6.2.2. Overall Analysis

The correlation table (table 6) shows that there is significantly negative correlation between quality of life and the groups (scored so that UK=1 and Kurdish=2). The negative correlation shows that Kurdish people reported lower perceived quality of life than those in the UK. A significant positive correlation is shown between quality of life and seizure severity, indicating that as seizures become more severe quality of life improves. A significant positive correlation is also found between quality of life and knowledge of epilepsy. This measure shows that better quality of life is associated with better knowledge.

A significant negative correlation is shown between perceived illness seriousness and quality of life (table 6); the more the participants felt their epilepsy is a serious condition the worse the quality of life. A significant negative correlation is shown between perceived stigma and quality of life. These results demonstrate that if people feel stigmatised because of their epilepsy they are more likely to report a lower quality of life. A significant negative correlation is also evident between depression and qualities of life, the more depressed people with epilepsy are the worse their quality of life.

A significant negative correlation is shown between groups and seizure severity, indicating that seizure severity is reported to be higher amongst the UK participants. There is also a significant negative correlation between groups and knowledge, showing that participants belonging to the UK group possess better knowledge of epilepsy. A significant positive correlation is shown between group belonging and perceived illness seriousness, indicating that those in the Kurdish group perceived their epilepsy to be more serious. A significant positive correlation is also shown between reporting higher depressive symptoms and groups; this suggests that those participants in the Kurdish group have reported more depressive symptoms compared to those in the UK group. A significant positive correlation is shown between perceived stigma and groups, suggesting that those in the Kurdistan group have reported higher scores in this measure compared the UK group.

Age has a positive significant correlation with seizure severity, showing that in this study reporting more severe their seizures increased with age. Age also has a positive significant correlation with knowledge, meaning the older the people with epilepsy the more knowledge they possess about their condition.

Seizure severity has a significant positive correlation with knowledge. Seizure severity has significant negative correlations with perceived illness seriousness, depression and perceived stigma.

Knowledge has significant negative correlations with perceived illness seriousness, depression and perceived stigma.

Perceived illness seriousness has significant positive correlations with depression and perceived stigma. Finally, perceived stigma has a significant positive correlation with depression, meaning those scoring high on perceived stigma have reported more depressed symptoms.

Table 6: The Pearson’s correlations and its significance between the model variables and quality of life

Variables	1	2	3	4	5	6	7	8	9
			Participants (n=170)						
1.Quality of life	–								
2. Group	-.281*	–							.
3. Age	.046	-.370*	–						
4. Gender	.045	-.135**	-.044	–					
5. Seizure Severity	.328*	-.163**	.230*	.124	–				
6. Knowledge	.280*	-.867*	.333*	.096	.189**	–			
7. Perceived Illness	-.628*	.138**	.008	-.006	-.231*	-.202**	–	.	.
8. Depression	-.700*	.279*	.080	-.050	-.224**	-.240*	.553*	–	.
9. Stigma	-.373*	.338*	-.094	-.040	-.229*	-.307*	.383*	.403*	–

Note: Significant levels are represented by *= p<.001, **= p<.01, and ***= p<.05

To test the hypotheses below, a hierarchical multiple regression analysis was used:

1. Based on previous literature, it is expected that seizure severity has a negative impact on quality of life; it is therefore hypothesised that participants in this study who scored high on the seizure severity scale will have reported significantly poorer quality of life.

2. It is predicted that participants in this study scoring high on the perceived illness seriousness scale will have reported significantly poorer quality of life.

The variables used to predict quality of life in this study were input into SPSS using four separate sequences of blocks. The sample size considered for the overall analysis of the regression was n=170, for a medium effect the estimated minimum sample size for this analysis based on eight predictor variables was 60 (Cohen, 1992; Maxwell, 2000). The method to calculate the sample was n=52 + number of predictor variables (Maxwell, 2000).

The data shows that it does not have multicollinearity (see Appendix 11.11), which means that the independent variables are not closely correlated to one another, the data also shows tolerance value for all variables are within normal range (over .01) and VIF values are all <10, (Hair et al, 2006).

Hierarchical multiple regression was used for the analysis to answer the research questions in this study. This allows the researcher to entere the variables sequentially according to reported theory and literature in this area (Field, 2005; Tabachnik & Fidell, 2007), in this case quality of life (Wilson & Cleary, 1995; Ferranset al., 2005; Wilbur et al., 2005; Taylor et al, 2011). This technique allowed the researcher to order the variables to be considered in the analysis; this was based on reported literature on the effects of epilepsy (Goffman, 1963; Doughty et al., 2003; Jacoby & Austin, 2007; WHO, 2010).

Step one of the regression analysis which was the demographic information including country of participation, age and gender showed a significant effect on the dependant variable which is quality of life, $F_{(3,166)} = 5.00$, $p<0.05$. However, after entering the seizure severity variable, the country of participation is no longer significant. The results also show that in step one, country of participation (scored so that UK participants=1 and Kurdistan participants=2) predicts quality of life and this is shown to be highly significant, $p<.000$. This result does change drastically by step four as it becomes an insignificant prediction (table 7). The analyses also demonstrate that the demographic variables, which included groups, age and gender, accounts for about 8% of the variance in the outcome of quality of life.

Experiencing depressive symptoms and how serious a person feels their epilepsy is accounts for more variance on the effects on quality of life and was highly significant, 60%, $p<.000$.

Step four was the measure used for perceived stigma, this variable has a significant variance on the quality of life, 60%, $p<.05$, and showed that it has a significant effect on quality of life, $F_{(8,161)} = 30.211$, $p< .000$, however, perceived stigma was not a significant predictor of quality of life.

The model used significantly proves that quality of life was predicted by the variables used in the samples. The above results were of the overall data collected from both the UK and Kurdistan.

Table 7: Summary of Hierarchical Multiple Regression Analysis for variables predicting the quality of life

Variables	**R^2**	**SE B**	**ß**	**Significance**
Step 1				
Group	.083**	3.525	-.306	**.000**
Age		.123	-.067	.408
Gender		3.363	.001	.991
Step 2				
Group	.178*	6.332	-.206	.158
Age		.119	-.133	.090
Gender		3.234	-.036	.622
Seizure Severity		.126	.313	**.000**
Knowledge of Epilepsy		.572	.090	.530
Step 3				
Group	.600*	4.599	-.066	.534
Age		.087	.029	.605
Gender		2.272	-.005	.920
Seizure Severity		.092	.128	**.018**
Knowledge of Epilepsy		.409	.101	.920
Perceived Illness Seriousness		.103	-.326	**.000**
Depression		.107	-.473	**.000**
Step 4				
Group	.600***	4.666	-.066	.542
Age		.087	.029	.606
Gender		2.279	-.005	.921
Seizure Severity		.093	.128	**.020**
Knowledge of Epilepsy		.410	.010	.920
Perceived Illness Seriousness		.105	-.325	**.000**
Depression		.109	-.473	**.000**
Perceived Stigma		.099	-.001	.988

Note: Significant level are represented by *= p<.001, **= p<.01, and ***= p<.05

6.2.3. Hypothesis one

In order to test hypothesis one, which stated that those participants who scored high on the seizure severity scale will have scored low on the quality of life scale, the scores for all participants were input into step two of the regression analysis, showed that seizure severity is a significant positive predictor of quality of life, $F_{(5,164)} = 7.099$, $p < .000$. The results showed that with every unit increase of reported seizure severity there is an increase in quality of life (table 7). This is not the result that was predicted, which is also demonstrated by the significant positive correlation above (table 6). This will be explored further at a later stage of the results section in this chapter, as the results will be analysed separately, UK and Kurdish groups, which could have an effect on the outcome of the results.

6.2.4. Hypothesis two

To test the hypothesis (two) which predicted that those participants scoring high on the perceived illness seriousness scale will have scored low on the quality of life scale was put into step three of the regression model. The analysis showed that with every unit increase of perceived illness seriousness there is ß=-.325 decrease in quality of life. This shows that perceived illness seriousness is a positive significant predictor of quality of life, $p < .000$ (table 7). This shows that if people with epilepsy perceived their condition to be a serious one it is more likely they will report poorer quality of life.

6.3. UK & Kurdistan

For this study to give a better insight into what the results meant, the data was split between the two groups, the UK and Kurdistan. In this part of the results the data will be looked at in separation but also in comparison. The data has been split by country of the data collection (country of participation), UK and Kurdish respondents in Northern Iraq. The similarities between the participants in the UK and the Kurdish groups are that all participants were diagnosed with epilepsy and over the age 18. The age range for the UK participants were between 18 to72 with a mean age of *M*=44, and the participants in the Kurdistan group were aged 18 to 80 with a mean age of *M*=34. Although not controlling for gender equally in this study, there were more females in both groups and the majority were either single or married across the board. There were also differences between the two groups. There were significant differences between the measures used in this study and group belonging of participants (table 8).

The hypotheses that will be tested in this section of the results will be:

3. It is hypothesised that those from the UK group will have scored significantly higher on the quality of life scale compared to those in the Kurdish group.
4. It is predicted that the Kurdish group will have significantly lower scores on the knowledge of epilepsy measure compared to the UK group.
5. Those in the UK group will have scored significantly lower on the perceived stigma scale compared to those in the Kurdish group.
6. It is predicted that the UK group will have scored significantly lower on the depression scale compared to the Kurdish group.
7. It is hypothesised that participants with epilepsy living in Kurdistan will report a significantly poorer quality of life compared to the participants with epilepsy in the UK group.

A Multivariate analysis of variance (MANOVA) test was run to check for Box's test of equality of covariance, to confirm differences between the groups (UK and Kurdistan) and the measures used. This was mainly to investigate whether the scores gained from participants across the groups were significantly different. Box's test checks the significance of the null hypothesis (Field, 2005) and should be non-significant; however, if any of the MANOVA assumptions are violated, such as normality and equal sample size and equality between groups, a significant result can be ignored. In this case as the samples were not equal between the groups, UK n=84 and Kurdistan n=88, and the sample size is of a larger capacity the significant Box's M test is acceptable. Box's M is 85.303 with F=3.909 which is highly significant p<.000. This indicates that further analyses between the groups are justified.

The descriptive statistics (table 8) show that knowledge of epilepsy mean total scores were higher among the UK group with 28 compared to 18 in the Kurdish group, indicating that the UK participants had greater knowledge of epilepsy. Mean total seizure severity scores were higher among the UK group with 46 compared to 41 in the Kurdish group; however, the mean total score for perceived illness seriousness was higher among the Kurdish group with 49 compared to 45.6 among the UK group, showing that the Kurdish participants perceived their condition to be more serious. Perceived stigma and depression scores were also higher among the Kurdish group compared to the UK group, although, quality of life scores were lower among the Kurdish group.

Table 8: The descriptive statistics for the measures used reporting the mean, SD and range of UK and Kurdish group

Variables	**Mean (SD)**		**Range (min-max)**	
	UK	Kurdish	UK	Kurdish
Knowledge of Epilepsy	27.71 (2.77)	18.22 (2.68)*	14 (19-33)	16 (13-29)
Seizure Severity	45.89 (11.38)	41.39 (13.86)*	45 (22.50-67.50)	57.50 (17.50-75)
Perceived Illness Seriousness	45.57 (12.51)	49.22 (13.24)**	57 (15-72)	63 (17-80)
Stigma	48.40 (15.48)	57.17 (7.33)**	74 (17-91)	41 (34-75)
Depression	18.79 (12.14)	25.94 (12.81)**	55.73 (0-55.73)	50 (4-54)
Quality of Life	56.52 (21.05)	43.96 (20.82)*	82.73 (13.18-95.91)	94.09 0-94.09)

Note: Significance levels are represented by *=p<.001, **=p<.01, and ***=p<.05

In an open section of the Illness Seriousness Perception participants were also asked what they thought the causes of their epilepsy was, they were given three spaces to give their written answers. The responses were collated and put into 12 categories overall. The UK participants reported that stress and trauma, brain damage/inconsistencies and other medical complications (epilepsy as a secondary condition) were the biggest causes of their condition, while the Kurdish group stated that stress and emotional trauma, other medical complication and other (this included ‘I don’t know’ and epilepsy) was the main reported cause of their epilepsy. The responses from the participants from both groups are reported in table 9.

Table 9: Possible causes of epilepsy as reported by the UK & Kurdish group

	Possible Causes of Epilepsy	**UK**		**Kurdish**	
		n	**%**	**n**	**%**
1.	Lifestyle	22	13.2	4	1.8
2.	Medical Complications	25	15	27	12.3
3.	Brain Damage/Inconsistencies	32	19.2	4	1.8
4.	Developmental	15	9	0	0
5.	Related to Childhood Illnesses	2	1.2	0	0
6.	Stress & Emotional Trauma	34	20.4	70	32
7.	Head Injury	13	7.8	16	7.3
8.	Environmental Factors	4	2.4	1	0.5
9.	Depression	4	2.4	1	0.5
10.	Hereditary	7	4.2	3	1.4
11.	Beaten/Tortured	2	1.2	5	2.3
12.	Other	7	4.2	88	40.2

6.3.1. UK & Kurdistan Analysis

To test the the remaining hypotheses, listed below, a MANOVA was used:

3. It is hypothesised that the participants in this study from the UK group will have reported significantly better quality of life compared to the participants in the Kurdish group.

4. It is predicted that the Kurdish group will have significantly lower scores on the knowledge of epilepsy measure compared to the UK group.

5. Those in the UK group will have scored significantly lower on the perceived stigma scale compared to those in the Kurdish group.

6. It is predicted that the UK group will have scored significantly lower on the depression scale compared to the Kurdish group.

7. It is hypothesised that participants with epilepsy living in Kurdistan will report a significantly poorer quality of life compared to the participants with epilepsy in the UK group.

Results from the tests of equality of group means in MANOVA demonstrated the difference between the two groups (UK & Kurdistan) and their mean scores, and whether the differences were significant. Seizure severity showed significant difference between the two group means, F=5.39, p<.05, the knowledge of epilepsy measure demonstrated a highly significant difference, F=519.98, p<.000, the depression measure used also showed strong significance, F=14.08, p<.000, with perceived stigma, F=22.85, p<.000 and quality of life also showing a highly significant result with F=15.47, p<.000. Although it is important to mention that the perceived illness seriousness measure did not show a significant difference between the two groups, F=3.45, p>.05. The results confirm that there is a strong significant difference between the UK and Kurdish groups in the variables used apart from the perceived illness seriousness which is not significant.

6.3.1. Hypothesis three

Hypothesis three, which states that participants from the UK group will score higher on the quality of life scale compared to the Kurdish group, the mean scores for the UK group was *M*=56.52 and Kurdish group *M*=43.96 which was significant at p<.000, therefore we accept this hypothesis that participants with epilepsy report to have a better quality of life in the UK compared to those in Kurdish group.

6.3.2. Hypothesis four

Hypothesis four predicted that the Kurdish group will have lower scores on the knowledge of epilepsy measure compared to the UK group. The average mean score for the UK was *M*=27.71 and the Kurdish group *M*=18.22, with p<.000, indicating a significant difference. This hypothesis is accepted as people with epilepsy in the UK group possess better knowledge of epilepsy compared to those in the Kurdish group.

6.3.3. Hypothesis five

The next hypothesis proposed that those in the UK group will have scored lower on the perceived stigma scale compared to those in the Kurdish group. The UK group scored an average of *M*=48.40 and those in the Kurdish group *M*=57.17, which was significant, p<.000, confirming that there those participants with epilepsy in Kurdistan have higher perception of stigma compared to those in the UK.

6.3.4. Hypothesis six

This hypothesis proposed that those in the UK group will have scored significantly lower on the depression scale compared to those in the Kurdish group. The UK group mean score of *M*=18.79 and those in the Kurdish group *M*=25.94, which was significant, p<.001, confirming that there those participants with epilepsy in Kurdistan have reported higher depressions symptoms compared to those in the UK. Depression has also shown to be a significant predictor of quality of life among participants with epilepsy in both the UK and Kurdish groups.

6.3.5. Hypothesis seven

The final hypothesis predicted that those participants with epilepsy living in Kurdistan will report a significantly poorer quality of life compared to those in the UK group. This hypothesis is accepted as the results showed a highly significant difference between the two groups, F=15.47, p<.000. Participanst in Kurdistan group with epilepsy have a significantly poorer quality of life compared to those with epilepsy in the UK.

Correlations reported from the analysis for the UK group (table 10) show a negative correlation for age, gender, perceived illness seriousness, depressive symptoms and perceived stigma with quality of life. Although, it appears that there is a significant negative correlation between perceived illness seriousness, depressive symptoms and perceived stigma with quality of life, showing that as participants have scored high on these measures they are more likely to report poorer quality of life.

Table 10: The Pearson's correlations and its significance for the UK group between the model variables and quality of life

Variables	1	2	3	4	5	6	7	8
			Participants (n=84)					
1.Quality of life	–							
2. Age	-.102	–						
3. Gender	-.124	-.326*	–					
4. Seizure Severity	.080	.192***	-.030	–				
5. Knowledge	.052	.080	.003	-.048	–			
6. Perceived Illness	-.672*	-.021	.149	.030	-.185***	–		
7. Depression	-.737*	.221***	-.073	-.067	.060	.489*	–	
8. Stigma	-.324*	.027	-.013	-.253**	-.053	.375*	.375*	–

Note: Significant level are represented by *= p<.001, **= p<.01, and ***= p<.05

The correlations and their significance reported for the Kurdish group (table 11) show that there is highly significant positive correlation between reported seizure severity and quality of life. A strong significant negative correlation between perceived illness seriousness, reported depressive symptoms and perceived stigma with quality of life (table 11), indicating the higher the participants have scored on these measures the lower the perceived quality of life. The Cronbach's alpha for the knoweldge of epilepsy measure for the Kurdish groups was very low, at α=.07, which may have influenced the results showing insignificance where in fact it may have been a significant correlation.

In comparison, the UK and the Kurdish group appear to have quite a lot in common, in that both sets of results appear to have a highly significant negative correlation between depressive symptoms, perceived illness seriousness and perceived stigma on quality of life. The results demonstrate that a person diagnosed with epilepsy and report feelings of depressive symptoms, perceive their condition to be serious and perceive stigma will report poorer quality of life. Among the Kurdish sample there is also a strong correlation between how severe participants feel their epilepsy is and their quality of life. The more severe the participants feel their epilepsy symptoms are the better the reported quality of life amongst the Kurdistan group.

Table 11: The Pearson's correlations and its significance for the Kurdish group between the model variables and quality of life

Variables	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**
				Participants (n=86)				
1.Quality of life	–							
2. Age	-.024	–						
3. Gender	.129	.127	–					
4. Seizure Severity	.478*	.183***	.206***	–				
5. Knowledge	.100	-.033	-.089	.220***	–			
6. Perceived Illness	-.572*	.151	-.104	-.398*	-.153	–		
7. Depression	-.618*	.188***	.038	-.283**	-.059	.587*	–	

8. Stigma	-.332*	.060	-.007	-.128	.015	.411*	.354*	–

Note: Significant levels are represented by *= p<.001, **= p<.01, and ***= p<.05

For further analysis, again, Hierarchical Linear Multiple Regression was used and the variables were put into the model using the same steps as previously, using sequential method.

Among both the UK and Kurdish groups (tables 12 & 13), show that depressive symptoms reported by the participants influenced quality of life, p<.000. Perceived illness seriousness was also a positive significant predictor of quality of life among the UK sample (table 12), p<.000, however, this was not the case for the Kurdish group, p>.05, (table 13).

The Regression model used for this analysis showed that age and gender were not good predictors of quality of life in both groups. Amongst the UK group, seizure severity and knowledge of epilepsy were not significant predictors of quality of life, however, this was not the case with the Kurdish group where it was significant (table 12), p<.01. The analysis showed that depressive symptoms and perceived illness seriousness had a strong significance in the quality of life of people with epilepsy in both the UK and Kurdish group (tables 12 & 13).

The analyses further show that variability accounts for about 4% of the outcome due to the demographic information collected in the UK and around 2% for the Kurdish group (tables 12 & 13). The total variability in quality of life as explained by seizure severity and knowledge of epilepsy is just over 5% in the UK sample compared to around 24% (p<.000) in the Kurdish sample. The variability in quality of life as explained by reported depressive symptoms and perceived illness seriousness is almost 69% (p<.000) in the UK compared to around 50% (p<.000) in the Kurdish sample. The total variability in the outcome of quality of life as explained by perceived stigma in the UK is 60% and about 52% in the Kurdish sample (tables 11 & 12).

The Regression model used significantly proves that quality of life can be predicted by some of the variables used in the samples. Amongst the UK group (table 12), step one of the regression analysis which was the demographics information including age and gender did not show a significant effect on quality of life, F $_{(2, 81)}$ = 1.60, p>.05, step two which was inclusive to seizure severity and knowledge of epilepsy did not prove to be have a significant effect on quality of life, F $_{(4, 79)}$ =1.144, p>.05. Step three which included perceived illness seriousness and depression significantly affect quality of life, F $_{(6,77)}$ = 28.046, p<.000, and step four which was the measure used for perceived stigma showed that it has a significant effect on quality of life, F $_{(7,76)}$ = 24.017, p< .000.

Table 12: Summary of Hierarchical Multiple Regression Analysis for variables predicting the quality of life for the UK group

Variables	**R^2**	**SE B**	**ß**	**Significance**
Step 1				
Age	.038	.173	-.159	.171
Gender		5.164	-.176	.131
Step 2				
Age	.055	.178	-.189	.115
Gender		5.190	-.182	.119
Seizure Severity		.270	.114	.311
Knowledge of Epilepsy		.836	.073	.507
Step 3				
Age	.686 *	.107	-.041	.566
Gender		3.083	.118	.091
Seizure Severity		.122	.060	.365
Knowledge of Epilepsy Perceived		.503	.019	.770
Illness Seriousness		.131	-.388	**.000**
Depression		.135	-.544	**.000**
Step 4				
Age	.608*	.107	-.043	.549
Gender		3.090	-.117	.093
Seizure Severity		.127	.075	.278
Knowledge of Epilepsy		.505	.021	.750
Perceived Illness Seriousness		.136	-.404	**.000**
Depression		.139	-.557	**.000**
Perceived Stigma		.101	.059	.428

Note: Significant levels are represented by *= p<.001

Step four of the model used in the Kurdish group (table 13) included depression and perceived illness seriousness measures which showed to be a good predictor of quality of life. Quality of life amongst the Kurdish participants was better predicted by seizure severity (table 13), p<.01 compared to the UK sample, p>.05. This step also showed a significant variance, R^2= .522, F $_{(7, 78)}$ 12.159, p<.000.

Amongst the Kurdish group, in step one of the regression analysis, which included age and gender, did not show to be a significant predictor of quality of life, $F_{(2, 83)} = .772$, $p > .05$. Step two of the model included seizure severity and knowledge of epilepsy measures which showed to significantly predict quality of life, $F_{(4, 81)} = 6.513$, $p < .000$. Step three of the regression model, which included perceived illness seriousness and depression, was significant , $F_{(6, 79)} = 14.114$, $p < .000$, and finally step four was also a significant predictor of quality of life, $F_{(7, 78)} = 12.159$, $p < .000$. Due to a low Cronbach's alpha, $\alpha=.07$, for the knowledge of epilepsy measure used in this study the results may have been affected to show insignificance where it may have been a significant outcome.

Table 13: Summary of Hierarchical Multiple Regression Analysis for variables predicting the quality of life for the Kurdish group

Variables	**R^2**	**SE B**	**ß**	**Significance**
Step 1				
Age	.018	.183	-.041	.709
Gender		4.580	-.134	.225
Step 2				
Age	.243*	.165	-.120	.228
Gender		4.181	.042	.677
Seizure Severity		.157	.493	**.000**
Knowledge of Epilepsy		.783	-.008	.934
Step 3				
Age	.517*	.139	.035	.675
Gender		3.418	.065	.428
Seizure Severity		.140	.251	**.008**
Knowledge of Epilepsy Perceived		.603	-.007	.934
Illness Seriousness		.161	-.222	**.035**
Depression		.161	-.426	**.000**
Step 4				
Age	.522*	.140	.033	.698
Gender		3.425	.067	.416
Seizure Severity		.140	.254	**.007**
Knowledge of Epilepsy		.640	-.002	.984
Perceived Illness Seriousness		.168	-.196	.072
Depression		.163	-.413	**.000**
Perceived Stigma		.249	-.074	.398

Note: Significant levels are represented by *= $p<.001$

The F values and significance for each step in the model indicate that amongst the UK sample there is a strong connection between reported illness perception and depressive symptoms on the outcome of quality of life. In this case we can predict that a person with epilepsy showing signs of depressive symptoms will report poorer quality of life. It is also clear that if a person diagnosed with epilepsy feels that their condition is serious, they are more likely to perceive a lower quality of life. This is also true if people with epilepsy perceive more stigmas because of their condition. Amongst the Kurdish group, however, it appears that there is a strong connection between seizure severity and depressive symptoms on quality of life. This study has shown that a person diagnosed with epilepsy in Kurdistan is more likely to report a better quality of life if they experience more severe seizures (table 12). The effects of depressive symptoms is similar as in groups, which is highly significant, so therefore, it can be put forward that depression is a variable strongly predictive of quality of life in the UK and Kurdistan population for people with epilepsy. Amongst the UK participants perceived illness seriousness is also a strong predictor of quality of life.

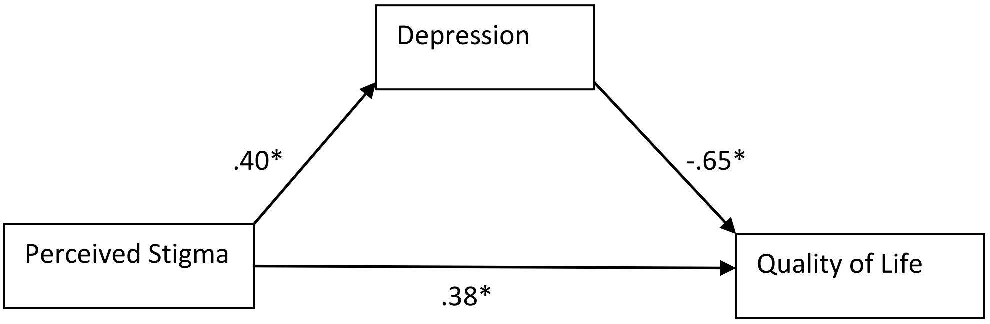
6.4. Further Analysis

In previous reported literature, stigma has been found to affect people with epilepsy and negatively impact quality of life (Suurmeijer, Reuvekamp, & Aldenkamp, 2001; Jacoby, 2002). In this study, although perceived stigma had a significant negative correlation with quality of life, it was not found to be a significant predictor of quality of life after Regression analysis. The decision was taken to further analyse the results to check for a mediating influence between perceived stigma and reported depressive symptoms. The decision to use depression as a mediator was based upon the vast reported literature in this area which has found depression to be a strong predictor of quality of life (Suurmeijer et al., 2001; Bishop & Allen, 2003; Johnson et al., 2004), as has been observed in this current study. People with epilepsy may experience stigma causing them to be depressed and consequently negatively impact on their quality of life (Suurmeijer et al., 2001).

The method for this analysis was based on Baron and Kenny’s (1986) model of mediation. This is where the predictor variable, perceived stigma, is mediated by another variable, depression, to influence the outcome variable, which was quality of life (Baron & Kenny, 1986). This procedure is carried out by running three separate regression analyses. The first was to check the mediating variable, in this case depression, on the independent variable, which was perceived stigma. The second regression was run between the dependant variable, which in this case was quality of life, and independent variable. The final regression was between the dependent variable on both the independent variable and mediating variable. For a mediating effect some conditions have to be met; perceived stigma has to affect depression in the first regression analysis; perceived stigma has to affect quality of life in the second regression and; depression must affect quality of life in the third regression. Furthermore, if these conditions are all met after analysis, the effect of perceived stigma on quality of life must be less in the third compared to the second regression analysis.

Following the above instructions (Baron & Kenny, 1986) the results show that mediation has taken place. The first mediation analysis was run for all participants with epilepsy. The model used for the mediation analysis was significant; the first regression analysis was significant at F=32.99, p<.000; the second regression analysis was also significant at F=28.47, p<.000; and the third regression also confirmed significance at F=81.96, p<.000. This suggests that perceived stigma mediated by depression can be a significant predictor of quality of life (figure 1).

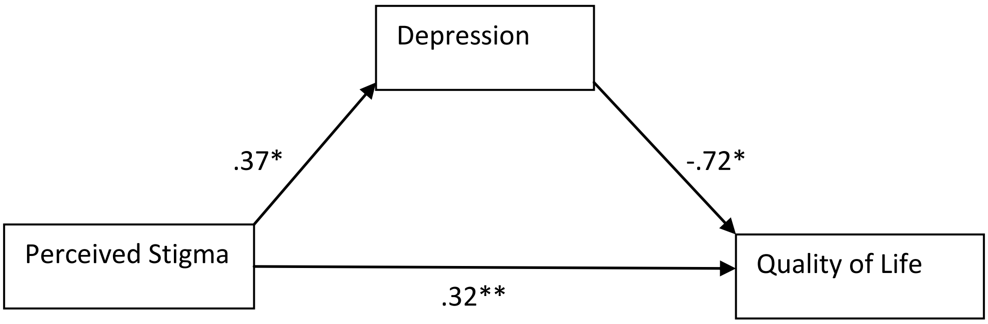
Figure 1: Mediation analysis results for all participants with epilepsy



Note: Significant levels are represented by *= p<.001

Further mediation analysis was carried out by splitting the data by country. This method proved to be significantfor an indirect effect. The first analysis was carried out for the UK group and showed that perceived stigma significantly affects depression as the first regression showed F=13.40, p<.000. Secondly, perceived stigma significantly affects quality of life, F=9.63, p<.003, thirdly the mediator, depression, significantly affects quality of life, F=48.59, p<.000. This analysis shows that the effect of perceived stigma on quality of life is considerably lower in the third regression compared to the second (figure 2). This analysis shows that perceived stigma is mediated by depression in the UK group, additionally, as a direct result of adding the mediator into the model the direction and significance of perceived stigma on quality of life has changed. This confirms that perceived stigma of people with epilepsy is indirectly influenced by depression in its negative impact on quality of life.

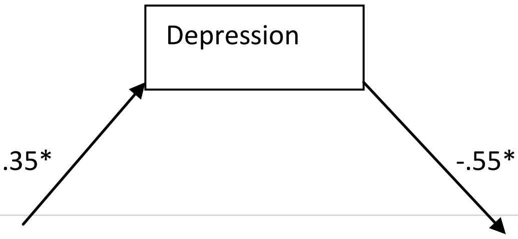
Figure 2: Mediation analysis results for the UK participants with epilepsy

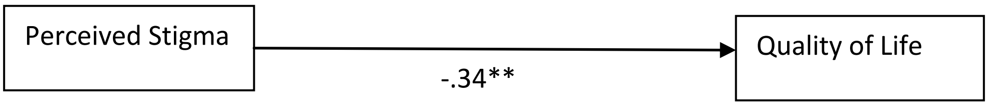


Note: Significant levels are represented by *= p<.001, and **= p<.01

Mediation analysis carried for those in the Kurdistan group also showed that this was a significant model to test for mediation effect; the first regression F=12.04, p<.000, the second regression F=11.31, p<.001, the third regression F=26.40, p<.000. This analysis has shown that perceived stigma is mediated by depression in the Kurdistan group (figure 3) according to the method and conditions set by Baron & Kenny (1986).

Figure 3: Mediation analysis results for the Kurdish participants with epilepsy

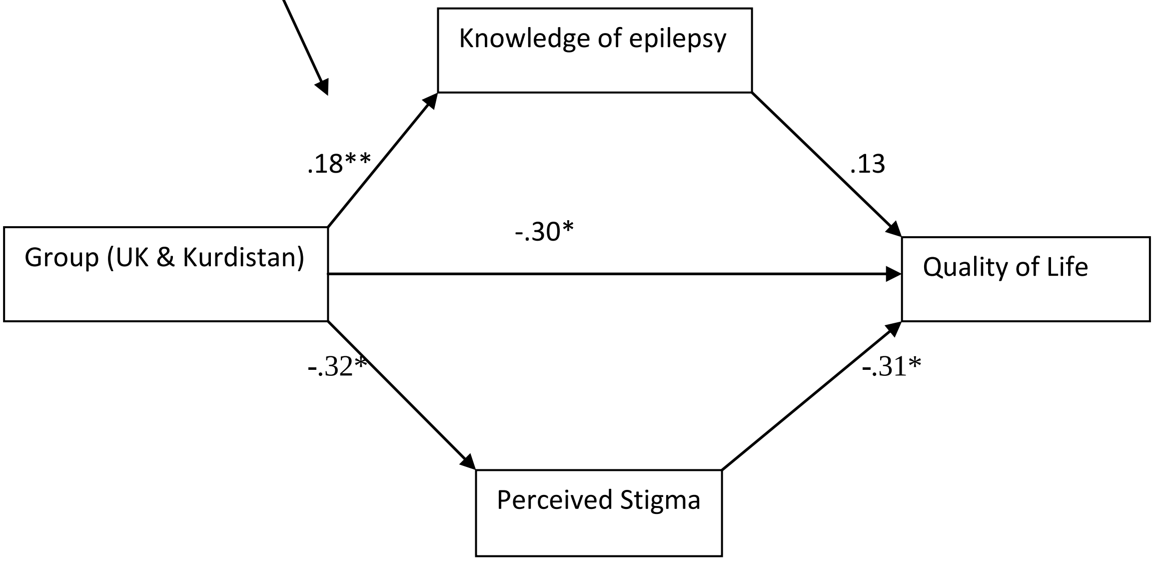




Note: Significant levels are represented by *= p<.001, and **= p<.01

Using the same procedure as above (Baron & Kenny, 1986), the final mediation was run for all participants with epilepsy to check wether group belonging was mediated by perceived stigma and knowledge of epilepsy on quality of life. The results were significant. The first regression was significant at F=18.00, p<.000; the second regression was significant at F=15.50, p<.000; and the final regression was also significant at F=12.00, p<.000. This analysis sugests that the group that participants belong to, mediated by perceived stigma and knowledge of epilepsy, can be significant predictors of quality of life. This analysis further shows that the effect of group belonging, mediated by perceived stigma is a significant predictor of quality of life. However, as a direct result of adding the mediator, knowledge of epilepsy, into the model the direction and significance of group belonging on quality of life has changed. This confirms that group belonging is indirectly influenced by knowledge of epilepsy in its negative impact on quality of life (figure 4). In this case, it appears that knowledge of epilepsy suppresses the the effects of group belonging on the outcome of quality of life.

Figure 4: Mediation analysis results for all participants with epilepsy



Note: Significant levels are represented by *= p<.001, and **= p<.01

6.5. Discussion

The overall results of this study have shown that participants from both the UK and Kurdish groups who reported more severe seizures had better quality of life. This contradicts the available literate that states that more severe seizures negatively impact quality of life (Harden et al., 2007; Bautista & Glen, 2009; Sancho et al., 2010; Taylor et al, 2011; Milovanović et al., 2014). This result was highly significant, showing that as people's seizures worsened their quality of life improved. Further analysis showed that seizure severity was still a significant positive predictor of quality of life amongst the Kurdish participants, but not amongst the UK group. It has been shown that with the use of mastery and social support as mediators for seizure severity has had a positive impact on quality of life (Amir at al., 1999). In further studies social support has been found to be a predictor of quality of life in people with epilepsy in Korea (Choi-Kwon, Chung, & Kim, 2003). In this research mastery and social support were not measured in order to carry out further analysis. Also, the results were strongly significant in an unexpected direction; additionally, direct influences as a result of seizure severity on quality of life are limited in its availability to make extensive comparisons.

A problematic observation concerning the seizure severity measure was that the Cronbach's alpha (α) was reported to be quite low, however, with the removal of item seven (7), the reliability of the measure increased from α=.336 to α=.527. This item questioned the length of time confusion lasts after a seizure, which stated: 'After my most severe seizures, my confusion lasts for:' and the options were: 'less than 1 minute', 'between 1 and 5 minutes', 'between 6 minutes and 1 hour', 'between 1 and 2 hours', 'more than 2 hours', and 'I never feel confused.' Also, due to the nature of epilepsy (ILAE, 2014) it is a possibility that the severity of seizures is unclear for those with the condition as in some cases the person experiencing the seizure is unconscious for the duration of the episode (Blumenfeld & Taylor, 2003). A better measure for this study may have been a frequency measure as this has been found to significantly impact on quality of life (Hout at al., 1997). It is a possibility that seizure severity, as a physiological symptom of epilepsy, does not have much of an influence on the outcome of quality of life as suggested by Wilson and Cleary

(1995). As a result, measuring seizure severity as a predictor has had a contradictory effect on the overall outcome of quality of life.

The Cronbach's alpha (α) for the knowledge of epilepsy measure used in this study was very low for the Kurdish group, α=.07. This was only when the groups (the UK and Kurdistan) were separated for further analyses. From the data it is not clear where the issue lies as the participants as a collective group (the UK and Kurdistan) showed good reliability, α=.80.

Quality of life was then looked at in relation to knowledge of epilepsy, which showed that those people with better knowledge of their condition report a better quality of life, this has been shown with asthma patients indicating that with better education followed better quality of life (Gallefoss et al., 1999). This is in line with research that has been reported in this area and that knowledge of epilepsy is different according to where in the world individuals live, have now been linked to quality of life (Doughty et al., 2003; WHO, 2010). Knowledge of epilepsy has been mainly reported in association with stigma (Tekle-Haimanot et al., 1991; Doughty et al., 2003; WHO, 2010) and the availability of literature looking at the impact of knowledge of chronic conditions on quality of life is not so readily available. Knowledge of epilepsy has been reported in relation to others' perception as this can influence negative attitudes and stigma concerning people with epilepsy (Mecarelli et al., 2007; Shehata & Mahran, 2011) and not so much on the knowledge of the person with epilepsy. This study has demonstrated that further investigations are imperative in this area.

People with epilepsy experience stigma and this negatively impacts on their quality of life (Jacoby, 2002). Furthermore, quality of life is expected to be poorer in people with epilepsy and this is teamed with high perceived stigma amongst some people with the condition (Kumari et al., 2009). Perceived stigma, in this study, negatively correlated with quality of life, participants who felt stigmatised because of their condition perceived to have poorer quality of life, and this is in line with other reported literature in this field (McLaughlin et al., 2008; Whatley et al., 2010). This is a similar finding that has been reported in regards to enacted and felt stigma (Youn et al., 2001), the higher the perception of stigma the more negative the impact on quality of life.

Further analysis of the data, using hierarchical multiple regression, indicated that country of participation in this study was a significant predictor of quality of life. This is in line with reported research that indicates where people live in the world affects the quality of their life (Doughty et al., 2003; Fernandes et al., 2008; Shakir, & Al-Asadi, 2012). This study has shown that people with epilepsy in the UK have reported better quality of life compared to those in the Kurdistan group, this may have some connections with reports that epilepsy is not adequately treated in the developing regions (Scott, Lhatoo, & Sanders, 2001). The results also showed that seizure severity, perceived illness seriousness and depression are significant predictors of quality of life. The measure that appears to be contradictory is seizure severity. Amir et al. (1999) found that the more severe people with epilepsy reported their seizures to be the less support they claimed to receive. Furthermore, seizure worry has been associated to impact negatively on quality of life (Loring et al., 2004), the lack of control and anticipation of seizures have also been known to affect those with epilepsy (Jacoby, 1992). Further investigations have to be carried to confirm this observation in the seizure severity variable.

The data was split by country of participation (the UK and Kurdistan). The results showed that seizure severity, knowledge of epilepsy, depression, perceived stigma and quality of life were all significantly different between the groups, except perceived illness seriousness which showed that the results did not significantly differ between the UK and Kurdish groups.

The analyses were further examined using hierarchical multiple regression. It was demonstrated that among the UK participants perceived illness seriousness and depression were significant in their prediction of quality of life. Participants with epilepsy living in the UK who reported more depressive symptoms (Mehndiratta & Sajatovic, 2013) and felt their epilepsy was a serious condition perceived to have lower quality of life. This is in line with other reported literature where depression has been associated with poor quality of life in people with epilepsy (Drinovac et al., 2015; Micoulaud-Franchi et al., 2015).

Due to the unavailability of research (Weinman & Petrie, 2013) into epilepsy and the seriousness of illness perception a comparison cannot be made in regards to the findings of the present study. This warrants further investigations to confirm and support the findings of this research. However, it is suggested that support groups are necessary for those diagnosed with epilepsy in order to gain a better understanding of their condition as this can impact on quality of life (Pais-Ribeiro, da Silva, Meneses, & Falco, 2007).

Among the Kurdish group, however, it was the seizure severity (as discussed earlier) and depression (as discussed above) that best predicted quality of life. Perceived illness seriousness was a significant predictor earlier in the model (step three) however, this measure was not a significant predictor of quality of life by the fourth and final step of the hierarchical regression analysis. These results show that for those with epilepsy living in Kurdistan seizure severity and depression are important factors in predicting their quality of life. The results for seizure severity, as discussed earlier, contradicts reported literature. The results from this study for the association between depression and quality of life are in line with others in the area (Boylan et al., 2004; Drinovac et al., 2015; Micoulaud-Franchi et al., 2015).

This study showed that there are distinct differences between the two groups where quality of life was concerned. It has been demonstrated that people in the UK tend to perceive a better quality of life and possess better knowledge of epilepsy, this may be due to the level of education of people with epilepsy (Ahmad, 2011) as better education has been associated with the perception of improved quality of life (Ohaeri, Awadalla, & Farah, 2009; Shakir, & Al-Asadi, 2012) and less perceived stigma (Doughty et al., 2003). It was also found that people in the Kurdish group with epilepsy perceive more depressive symptoms than those in the UK group; this may be related to the lack of knowledge and higher perceived stigma in the less developed regions (WHO, 2010). Those in the Kurdish group experienced higher perception of stigma compared to those in the UK group. There is a lack of research in these regions (WHO, 2010); however, higher perceived stigma has been related to where a person lives especially in less developed areas of the world (WHO, 2010; Tedrus et al., 2013).

In this study, participants in the UK group have reported to experience more severe seizures compared to those in the Kurdish group. This may be due to denial as it is sometimes used as part of the coping process with epilepsy (Liveh et al., 2001) amongst the participants from Kurdistan, perhaps indicating that they are not comfortable with their diagnosis. It appears from the results of this study that those people with epilepsy living in the UK report to have a better quality of life. This may be due to participants in the UK not perceiving their epilepsy as a serious condition and they do not report to be as depressed as those living in Kurdistan. It has again been shown that where a person lives affects those with epilepsy and their quality of life.

This study has shown support where stigma is concerned. Stigma was one of the variables in this research that was the centre of interest, especially bearing in mind the two different groups that data was collected from. The types of stigma, *felt* or *enacted* were not differentiated for this study (Scambler & Hopkins, 1990; Scambler, 1993; Jacoby & Austin, 2007). However, in the previous study (chapter 5) there appeared to a difference between the UK and Kurdistan group in regards to the types of stigma participants with epilepsy perceived. It appeared that *felt* stigma was more apparent among the UK participants, whilst *enacted* stigma was more prevalent among the Kurdish participants. Perceived stigma is not always associated with feelings of inadequacy or inferiority but could influence self-esteem (King et al., 2007).

Stigma was found to be highly correlated with quality of life but was not significant in its prediction of quality of life in either group. It may be that perceived stigma has an effect on depression and in turn depression affects quality of life. Stigma may have an indirect effect on quality of life, via a mediator, as a significant prediction was not observed among the UK or the Kurdish group. With the help of further analysis in a mediation procedure, it was found that perceived stigma is indeed a significant predictor of quality of life, with depression as a mediating variable. This was confirmed for all participants as a whole group and separated by the UK and Kurdistan sub-groups. Whilst perceived stigma indirectly influences quality of life for people with epilepsy in the UK as well, the mediation analysis for the Kurdish group showed classic meditation in regards to the beta values and direction. This strongly indicates that people with epilepsy in Kurdistan in Northern Iraq perceive high levels of stigma which influences depression and in turn negatively impacts on their quality of life. These results are in line with other reported literature where depression and stigma have been found to be significant predictors of quality of life (Whatley et al., 2010). In a European study more than half of people with epilepsy have felt stigmatised because of their condition (Baker, 2002) this shows that it is important to highlight this issue once again as this can have a devastating effect on quality of life as previously mentioned.

The *Cognitive Theory of Depression* (Beck, 2002) proposes that depression is a consequence of three factors. This includes the individual's negative thoughts about themselves, negative thoughts about the environment and negative thoughts about future prospects. Depression appears to be an issue for those diagnosed with epilepsy, and this is not difficult to understand why. Having a diagnosis of epilepsy could lead those with the condition to associate negative thoughts about themselves because of their condition but also the anticipated stigma from their society. Negative feeling about their future prospects could be exacerbated by the anticipated stigma and being associated with a 'discreditable' condition (Goffman, 1963). This could also be related to the restrictions that people with epilepsy could face because of their condition, in regards to employment (Jacoby & Austin, 2007), education and marriage prospects (WHO, 2010; Ahmad, 2011; Abdulla, 2014). From these studies, it appears that depression and stigma are more closely intertwined than previously noted. Epilepsy is a 'discreditable' condition and those diagnosed could, potentially, be side-lined and be perceived as less valued members in their society (Goffman, 1963). This affects the overall identity of individuals and can take away from the image that individuals have created for themselves (Goffman, 1969). Depending on where in the world people live, individuals have different expectations and responsibilities of themselves and others have from them, and the pressures of maintaining this normality could prove overwhelming for the individual. It is also worth mentioning that although, the symptoms can be somewhat hidden, the uncertainly on when a seizure can occur can also add to the burdens of having epilepsy. This could be particularly relevant for those in the Kurdish group, as people are expected to maintain their identity and strength of character, not only for themselves but also for their family.

Other important observations were made among the UK group. Depression was positively correlated with perceived illness seriousness, meaning that if people with epilepsy in the UK felt their condition was serious the reported depressive symptoms increased. Additionally, depression was also positively correlated with age; there was an increase in reported depressive symptoms with the increase in age of participants. Depression has previously been associated with women of childbearing age with epilepsy (Beghi, Roncolato, & Visona, 2004). Depression was further positively correlated with perceived stigma, the more participants' perceived stigma, the more reported depressive symptoms. These were all significant observations. A significant positive correlation was also observed with knowledge of epilepsy and perceived illness seriousness; the more knowledgeable the participants were about epilepsy, the more serious participants felt their condition was.

Amongst the Kurdish group, a positive significant correlation was observed between age and seizure severity and depression. Females reported more severe seizures compared to males. Seizure severity was also positively correlated with knowledge of epilepsy; the increase in reported knowledge of epilepsy meant an increase in seizure severity reports. Seizure severity was also negatively correlated with perceived illness seriousness and depression. Perceived illness seriousness was observed to be positively correlated with depression, the more serious people with epilepsy felt their condition was the more depressive symptoms they reported.

There were limitations related to this study. One of the obvious limitations of this study relates to the measure used for seizure severity and item seven (as discussed earlier). Another limitation of this study relates to an item in the knowledge of epilepsy measure. Item 20 stated ''if you forget to take antiepileptic drug for a day, it is usually OK to take two doses together''. The correct response to this item is that it is a ‘true’ statement according to the measure, however, this has been debated by medical practitioners whether this is actually the correct advice (Doughty et al., 2003). Most of the participants in the UK selected that it was a ‘False’ (n=79) statement and most of the Kurdish participants stated that it was a ‘False’ (67) statements, and received a score of ‘zero’ as a result which would affect the outcome of the results. This item in the questionnaire has proved problematic and requires consideration (Doughty et al., 2003).

Additional issues as a result of this study include lack of reported literatures to support or disprove the findings. Further research needs to be undertaken in order to clarify some of the findings, such as seizure severity. Additionally, data collection in Kurdistan, Northern Iraq, is a relatively new concept which may influence participant responses, to what extend is unknown.

To summarise this study, it is shown that there is one main similarity and difference in people with epilepsy in the UK and the Kurdish group. The similarity is that in both groups it was observed that perceived stigma is significantly negatively correlated with quality of life and the main difference between the two groups is that the UK has a significantly better overall quality of life compared to those living in Kurdistan, Northern Iraq. The best predictors of quality of life in the UK are depression and perceived illness seriousness, and the Kurdish community show that strong predictors of quality of life lay in how severe they feel their epilepsy is and reported depressive symptoms.

Depression has shown to be a strong predictor of quality of life with all people with epilepsy. Furthermore, perceived stigma, mediated by depression, has also shown to be a significant predictor of quality of life in people with epilepsy. It is also important to mention that among the Kurdish group perceived illness seriousness was approaching significance in being a predictor of quality of life. In short, as suggested, people with epilepsy will perceive an improvement to their quality of life if they managed their epilepsy better, are not as isolated and depressed and felt fewer stigmas from their society members (Suurmeijer et al., 2001).

Chapter 7: Quantitative Study of People without Epilepsy

This chapter looks at the data collected from 316 participants without epilepsy from the UK and Kurdistan concerning those with the condition. The results are first looked at collectively then compared between the UK and the Kurdish group. Analyses were carried out using ANCOVA (Analysis of Covariance), Multivariate General Linear Model and Linear Regression; this is then followed by a discussion based on the results gained from the study.

Negative attitudes and stigma are concerns that people with epilepsy have to deal with every day; this is especially true of areas of less developed regions, possibly due to lack of research and knowledge (Jacoby, Snape, & Baker, 2005; WHO, 2010). A study inclusive of 1,694 participants has shown that people living in the UK are generally well informed about epilepsy and have positive attitudes toward those with the condition (Jacoby et al., 2004). It is further proposed that familiarity is the best predictor of good knowledge and positive attitudes towards those with epilepsy, which have been associated with being female and higher educational attainments (Jacoby et al., 2004).

An only study reported from Kurdistan in Northern Iraq is that by Abdulla (2014) looking at others' knowledge and perceptions of people with epilepsy. This study found that knowledge of epilepsy was poor and this was paired with negative attitudes towards those with the condition (Abdulla, 2014). Further studies and information campaigns are essential as misinformation and negative attitudes affect those with epilepsy, which ultimately affect their quality of life (Abdulla, 2014).

As reported in the previous study (chapter six) perceived stigma affects people with epilepsy, and together with depression have been found to best predict quality of life. Chapter six was important in understanding how people with epilepsy felt in regards to their quality of life. The way others perceive epilepsy in society affects those with the condition which makes this study an important contribution to the overall understanding of the experiences of people with the epilepsy. The perceived stigma that is reported by people with epilepsy is associated with the quality of life of those with the condition. The purpose of this investigation was to check participant level of knowledge of epilepsy and the effects on stigma in the general population in the UK and Kurdistan. The lack of knowledge can lead to negative attitudes and stigma concerning those with epilepsy and this can negatively impact on the quality of life of those with the condition (WHO, 2010).

This study will test the hypotheses:

1. Familiarity has been associated with knowledge; it is therefore predicted that those who knew or had known someone with epilepsy will have significantly better knowledge of the condition.

2. According to literature better knowledge can lower negative attitudes and stigma concerning people with epilepsy; it is therefore hypothesised that those participants with better knowledge of epilepsy will have scored significantly lower on the stigma scale used in this study.

3. It is predicted that those participants in the Kurdish group will have scored significantly higher on the stigma scale of epilepsy compared to those in the UK group.

7.1. Methods Section

7.1.1. Design

A quantitative design was used to test the hypotheses (above) in this study and to measure the relationship between knowledge of epilepsy and stigma concerning those with the condition. A quantitative method was more suitable for this study for similar reasons as explained in study two for people with epilepsy (chapter 5). A quantitative methods design tests hypotheses and checks for relationships in the data (Yaremko, 1986). Furthermore, a quantitative design takes into consideration large samples, is less time consuming and objective (Creswell, 2009, 2013).

7.1.2. Participants

The Kurdish participants were all born and raised in their country of origin, this was mainly due to the inability to travel to and from Kurdistan because of political instability, also, those who emigrate often do not return for resettlement. Furthermore, because of the political instability of the region people from other countries do not immigrate to Kurdistan, which means that those in the Kurdish study have not been influenced by the knowledge and perceptions of non-natives. The UK participants, however, were restricted as to their participation; they were controlled for a minimum of 5 years residence in the UK to be included in this study. Due to the cosmopolitan nature of the UK society, where participants originated from could influence the outcome of the study, this was to control for long and short-term residents and take away the influence of non-UK participants. Other inclusion criteria were that participants were over the age of 18 and were not diagnosed with epilepsy.

7.1.3. Ethical Issues

Ethical approval was gained from Brunel University Psychology Research Ethics Committee (Appendix 10.1).

7.1.4. Measures

Back translation was used in this study for all questionnaires carried out in Kurdistan (Brislin, 1970; Harkness, Van de Vijver, & Mohler, 2003), please also see methods section for people with epilepsy study (chapter 6, section 6.1.4).

At the beginning of the questionnaire there was an introduction which stated ‘‘Hello, thank you for agreeing to take part in this questionnaire. The following questions are about you, please answer as truthfully as you can. There are no right or wrong answer, I am only interested in your views’’, followed by demographics which included age, gender, marital status, occupation, highest educational qualification, country/town of birth, country/town of residence (if different from birth) and time at place of residence. The participants were also asked ‘‘Do you know or have you ever known anyone who had epilepsy?’’, ‘‘Would you object to a person with epilepsy marrying a close relative of yours (brothers, sisters, or child)?’’, ‘‘Would you object to having any of your (eventual) children associate with persons who sometimes had epileptic seizures in school or in a playground?’’, and ‘‘Do you think that, in general, persons with epilepsy should be employed at the same jobs as other people?’’ (Young et al., 2002).

The demographic information section was the followed by Knowledge of Epilepsy (Doughty et al., 2003), and Stigma Scale of Epilepsy (SSE) (Fernandes et al., 2007b, 2007c). Each measure included its own instructions followed by the items in the questionnaires. At the end of the questionnaires participants were thanked for their time and for taking part in the study. For the UK participants, restrictions were put on the Survey Monkey questionnaires in that participants were unable to proceed unless they made one selection from each item and were unable to go back on questionnaires once they left the page.

7.1.4.1. Knowledge of Epilepsy

Knowledge of epilepsy was measured with the same scale used in study two (please see chapter 6, section 6.1.4.1.) (Doughty et al., 2003). This measure contained 34 items in which participants were able to choose either a ‘True’ or ‘False’ option, and it primarily looked at participants’ level of knowledge in epilepsy. In total there were 92 missing items from the questionnaires between all participants from both groups. As there were no instructions from the authors, a value of ‘0’ was given for each missing item.

7.1.4.2. Stigma

Perception of stigma in this study was measured by using the Stigma Scale of Epilepsy (Fernandes et al., 2007b, 2007c) which contained 24 items looking at other people’s attitudes concerning those with epilepsy. This measure was the most suitable for this study as the original questionnaire was used across different areas and was validated for use in regions of limited resources, as is the case for Kurdistan. This was also a strong measure to use as the reported Cronbach's alpha was $\alpha = 0.88$. The instructions given to participants were ‘‘After reading each of the following questions, please indicate your thoughts on the following scale to show your opinions about epilepsy’’. An example of one of the items was ‘‘Do you think people with epilepsy feel able to control their own epilepsy?’’ and the options for participants to choose from were ‘Not at all’, ‘A little’, ‘A lot’, and ‘Totally’. Items 1 and 4g were reverse coded and scores were calculated following directions from the authors: [(sum of all answered items-number of answered items) ×100] ⁄ maximum score possible-minimum score possible). Higher scores represented higher feelings stigma. There were seven missing items from the overall participant responses. There were no instructions from the authors on how to deal with missing data, after reverse coding, the decision was taken to insert ‘0’ for each missing item in SPSS.

7.1.5.1. UK Sample Procedure

For the UK sample, the details of the studies were sent out to researcher's personal contacts from a private email account and asked all receipients to circulate to anyone who may be willing to participate, known as snowball sampling (Breakwell et al., 2001), (see also chapter 5, section 5.1.3.). The research details were also posted on Face book and LinkedIn regularly to ensure that those willing to take part were given considerable opportunity to do so. The UK participants were recruited from Epilepsy Action weekend conferences, parents from primary schools (teachers, staff and parents included) and Brunel University (see chapter 6, section 6.1.5. for detailed procedure). Data collection continued for about 2 years to allow good exposure to the research and for participants to take part. Questionnaires were made available on Survey Monkey for the UK group. The online questionnaire's first page was the consent form of which participants had to tick to show they were happy to continue with the questionnaire, if this was left unmarked, the participants would not be able to continue with the questionnaire. After the demographics section any items that were not completed the system would not allow participants to continue, this measure was put in place to ensure forms were filled out completely, any forms that were not completely filled in were disregarded. In total there were 80 paper copies were made for the UK group and 40 completed forms were returned. There 94 responses from the online survey database, but only 76 had fully completed the forms. This meant that 18 online questionnaires were not used in the analysis.

7.1.5.2. Kurdish Sample Procedure

Participants in the Kurdistan group were recruited from schools (teachers and other staff), shopping centres and personal contacts. Due to the unavailability of resources, electronic copies of the questionnaire were not an option for the Kurdish participants and they were only provided with paper copies of the questionnaires. In total 250 questionnaires were printed for the Kurdish group, eight of which could not be used as they were incomplete and 42 were not returned leaving 200 completed questionnaires for this group.

7.1.5.3. General Procedure

Potential participants were approached and given a brief description of the study and were asked if they would participate. Some agreed to fill in the questionnaire straight away, for those who agreed the consent form was highlighted to read and sign, all participants were required to sign a consent form prior to starting the questionnaire. Once the participants were happy they were asked to read all the questions carefully and ensure all sections were completed. Some potential participants preferred to take the questionnaires home and they were provided with a stamped and addressed envelope. As explained in the previous study (see also chapter six, sub-section 6.1.5.) participants were helped when requested.

All participants were provided with a debrief form and thanked for their participation. Contact details, in the form of an email, was highlighted on the consent and debrief form for all participants, should they need to make contact in regards to the study.

7.1.6. Data Analysis

All data collected via questionnaires were entered into SPSS, accuracy was checked at interval stages of the data input several times, and also using SPSS, frequencies were checked to ensure correction of data entry and the reliability of measures used. The data was checked for normality and the values were within acceptable level of between +1 to -1 (see chapter 6, section 6.1.6. for full details). Knowledge of epilepsy had a value for skewness=.183 and for kurtosis=-.785, the stigma scale had values of skewness=.222, and kurtosis=-.240, showing that the data is distributed within the normal range (see chapter 6, section 6.1.6. for full details). The data was also checked for reliability using Cronbach's alpha. The reliability for Knowledge of Epilepsy in this study for the whole group is α=.74, α=.70 for the UK group and α=.35 for the Kurdistan group. In this study, the reliability for the Stigma scale for the whole group is α=.85, α=.90 for the UK group and α=.82 for the Kurdistan group. (α) =.848 for Stigma scale and α=.740 for knowledge of epilepsy, showing that the measures used were very reliable.

The data was checked for outliers and the knowledge of epilepsy measure used was within normal distribution and outliers were not detected, however, the tests (using SPSS) run highlighted one outliers for the measure used for the stigma scale. Only one outlier was identified and the decision was made to leave the outlier as it was a true response of this particular participant.

7.2. Results

For this study, knowledge concerning epilepsy (knowledge of epilepsy) and feeling of stigma concerning others with the condition (stigma scale of epilepsy) were investigated.

7.2.1. Participant Characteristics

This study included 316 participants. The participant characteristics of this study are below (table 14).

Table 14: Participant characteristics of people without epilepsy for the UK and Kurdistan groups

	UK			Kurdistan			
	n	**%**	**Total n (%)**	**n**	**%**	**Total n (%)**	**Significance**
Age							
Mean	39		116 (100)	32		200 (100)	.00
Minimum	19			18			.02
Maximum	73			68			.00
Gender							
Male	26	22.4		88	44		.00
Female	90	77.6		111	55.5		.00
Missing	/	/		1	.5		
Marital Status							
Single	40	34.5		85	42.5		.08
Married	60	51.7		100	50		.40
Divorced	9	7.8		5	2.5		.01
Widowed	3	2.6		2	1		.14
Living with Partner	3	2.6		/	/		
Separated	/	/		/	/		
Missing	1	.9		8	4		.05
Occupation							
Student	9	7.8		46	23		.00
Teacher/Lecturer	14	12.1		51	25.5		.00
Office Worker	20	17.2		2	1		.00
Civil Servant	2	1.7		33	16.5		.00
Housewife/Husband	6	5.2		6	3		.20
Unemployed	2	1.7		/	/		
Other	56	48.3		36	18		.00

Missing	7	6	26	13	.02
Education					
Illiterate	/	/	2	1	
Primary School	/	/	15	7.5	
Secondary School	35	30.2	58	29	.41
Diploma	5	4.3	59	29.5	.00
Undergraduate	34	29.3	54	27	.33
Postgraduate	34	29.3	8	4	.00
Missing	8	6.9	4	2	.01

7.2.2. Study Characteristics

The descriptive statistics for participant responses to the questionnaire are shown in table 15, showing that there is a large variance between the levels of knowledge of epilepsy amongst the participants. This is also true for the participant responses for the stigma scale used. This shows that just like knowledge of epilepsy, there is a large variance between perceptions of stigma concerning those with epilepsy. The descriptive statistics for the UK group show that the knowledge of epilepsy measure had a high range, showing that in the UK knowledge of epilepsy is quite varied (table 15). It appears that those participants in the UK group have a higher mean (*M*=25.83) compared to the Kurdish group (*M*=18.61), (table 15). The stigma scale used does not show a great deal of difference between the mean scores, which is not significant. This does show that stigma appears to be quite similar between both groups.

Table 15: Descriptive statistics for the measures used reporting mean, SD and range for the UK and Kurdistan groups

		UK		**Kurdistan**	
	Variables	Mean (*SD*)	Range (min-max)	Mean (*SD*)	Range (min-max)
1	Knowledge of epilepsy	25.83 (4.02)	19 (13-32)	18.61 (3.25)*	17 (10-27)

2	Stigma scale of epilepsy	45.72 (15.95)	70.83 (12.50-83.33)	45.87 (14.24)	79.17 (6.94-86.11)

Note: Significant level are represented by *= p<.001

7.2.3. Analysis

The two measures were analysed using the Pearson’s correlation coefficient and the results showed that the knowledge of epilepsy measure has significant negative correlation with stigma concerning people with epilepsy, *r*=-.173, *p*<.01. The results demonstrate that people who had better knowledge of epilepsy perceived less stigma concerning those with the condition. Furthermore, those indicating to have more stigma about people with epilepsy had less knowledge about the condition. This shows that in this study, knowledge about epilepsy is significantly correlated with stigma felt in regards to others with the condition.

An independent t-test was used to test hypothesis one which predicted that those participants who know or had known someone with epilepsy will have a better knowledge about the condition, The results showed that there was a significant difference between having personal knowledge of others with epilepsy (*M*=22.22, *SD*=4.79) and not having personal knowledge of others with epilepsy (*M*=19.16, *SD*=4.77); t ($_{310}$) =5.27, p<.000, *d*=0.64, and how much knowledge participants had concerning epilepsy.

7.2.4. Hypothesis One

It was hypothesised that those who knew or had known someone with epilepsy would have better knowledge about the condition. This was tested by running an independent t-test, the results demonstrated a significant relationship between having personal knowledge of others with epilepsy and the amount of knowledge participants had about the condition. The hypothesis stating that knowledge of epilepsy is increased by knowing someone with the condition is accepted.

Analysis of Covariance (ANCOVA) was used to check the second hypothesis which looked at the relationship between personal knowledge of others with epilepsy, knowledge concerning the condition, and groups (the UK and Kurdistan) with stigma concerning those with epilepsy. The results showed that knowledge concerning epilepsy was a significant positive predictor of perceived stigma about others with the condition, F $(_{1,307})$ =13.23, p<.000, and group belonging was also a positive significant predictor, F $(_{1,307})$ =7.02, p<.008. However, personal knowledge of others with epilepsy was not a significant predictor of the level of stigma concerning others with the condition.

7.2.5. Hypothesis Two

It was predicted that those participants with better knowledge about epilepsy will have scored lower on the stigma scale. By running an ANCOVA, it was demonstrated that knowledge of epilepsy was a significant positive predictor of stigma about others with epilepsy. This hypothesis is accepted as there is a clear and significant relationship between the level of knowledge about epilepsy and the amount of stigma about others with the condition.

7.3. Subsequent Analysis

Besides measuring knowledge of epilepsy and stigma, participants were also asked if they have known anyone with epilepsy, whether they would object to associate by marriage, if they would allow their children to play with another child with epilepsy and if people with epilepsy should be employed at the same jobs (Young et al., 2002). Using Pearson's Chi-Square (χ^2) statistics, the details of the answers given by participants are shown below (table 18). Table 16 shows that the majority of participants have reported to have known someone with epilepsy, this appears to have resonated with accepting someone close to them marrying a person with epilepsy. The response to allowing their children to play with another child with epilepsy was positive as most stated they would not object, and the majority of participants felt that people with epilepsy should be employed at the same jobs. The table (16) does show that there is a difference between the responses indicated by the participants in the UK group compared to those in the Kurdistan group. This will be explored further later in this chapter.

Table 16: Descriptive statistics for participants' responses in number and percentage

		UK	**Kurd.**		**UK**	**Kurd.**		**UK**	**Kurd.**			
	Measures	**Yes** **n (%)**		**Total**	**No** **n (%)**		**Total**	**Sub-total** **n (%)**		**Total**	(χ^2)	**Sign.**
1	Do you know or have known anyone who had epilepsy?	86 (41%)	125 (59%)	**211**	29 (29%)	72 (71%)	**101**	115 (37%)	197 (63%)	**312**	4.26	**.025**
2	Would you object to a person with epilepsy marrying a close relative of yours (brothers, sisters, or child)?	11 (10%)	94 (90%)	**105**	103 (50%)	103 (50%)	**206**	114 (37%)	197 (63%)	**311**	46.80	**.000**
3	Would you object to having any of your (eventual) children associate with a person who sometimes had epileptic seizures in school or in a playground?	3 (6%)	46 (94%)	**49**	113 (43%)	152 (57%)	**265**	116 (37%)	198 (63%)	**314**	23.70	**.000**
4	Do you think that, in general, persons with epilepsy should be employed at the same jobs as other people?	105 (53%)	92 (47%)	**197**	11 (10%)	102 (90%)	**113**	116 (37%)	194 (63%)	**310**	58.20	**.000**

7.3.1. Further Analysis

A Multivariate General Linear Model was used to further analyse the results for the Knowledge of Epilepsy measure. In response to 'Do you know or have known anyone who had epilepsy?' the results showed that this was a significant outcome with F=30.07, p<.00, indicating that knowing someone with epilepsy positively influenced how well-informed people were about the condition. In response to 'Would you object to a person with epilepsy marrying a close relative of yours (brothers, sisters, or child)?' the results indicated that this too was a significant result with F=7.02, p<.008, showing that better knowledge of epilepsy positively influenced future intentions. In response to 'Would you object to having any of your (eventual) children associate with a person who sometimes had epileptic seizures in school or in a playground?' the results showed another positive significant effect, F= 15.92, p<.000. When asked 'Do you think that, in general, persons with epilepsy should be employed at the same jobs as other people?' the results was again a positive significant result, with F= 21.70, p<.000.

Using the same analysis, Multivariate General Linear Model, the scores for Stigma Scale of Epilepsy were analysed in response to the questions as above. In response to 'Do you know or have known anyone who had epilepsy?' the results showed a significant effect, F=6.35, p<.012, indicating that knowing someone with epilepsy positively influenced stigma concerning those with the condition. The results for the next three questions, 'Would you object to a person with epilepsy marrying a close relative of yours (brothers, sisters, or child)?', 'Would you object to having any of your (eventual) children associate with a person who sometimes had epileptic seizures in school or in a playground?' and 'Do you think that, in general, persons with epilepsy should be employed at the same jobs as other people?' did not show to be significantly influenced by perception of stigma concerning those with epilepsy.

The analyses were investigated where education was concerned. Multiple linear regression was used to look at the level of education and whether this had any effect on the level of knowledge participants had on epilepsy and their feelings of stigma concerning people with epilepsy. The results showed that the level of education is a positive significant predictor of Knowledge of Epilepsy, $F_{(1,302)}=28.35$, $p<.00$, $R^2=.083$. The results further showed that education is also a positive significant predictor of the stigma others have about those with epilepsy, $F_{(1,302)}=5.15$, $p<.024$, R2=.017. These results show that with higher educational attainments, the level of knowledge about epilepsy is increased and stigma concerning people with the condition is reduced. The low Crohnbach's alpha, α=.35, for the knolwedg of epilepsy measure could have had a negative influence on the significance levels in this study.

7.4. UK & Kurdistan

In this part of the results, the data has been split by country of participation. There were a total of 316 participants of which 116 were from the UK group and 200 from the Kurdish group. The groups were comparable in this study as participants were not diagnosed with epilepsy and all over the age of 18. The UK participants were aged 19 to 73 with a mean age of M=39; and the Kurdish participants were aged 18 to 68 with a mean age of M=32. There were more female participants than males and the majority were either single or married in both the UK and Kurdish groups.

Due to the separation of the participants according to group, a reminder of the hypothesis that will be tested in this section:

3. It is predicted that those participants in the Kurdish group will have scored significantly higher on the stigma scale of epilepsy compared to those in the UK group.

7.4.1. Analysis

To check the data for relationships, Pearson's correlations were used. The results show that knowledge of epilepsy was significantly negatively correlated with the stigma scale in this study, r=-.74, p<.001 among the UK group, as well as those in the Kurdish group, r=-.217, p<.001, which was also highly significant. This shows that those participants with better knowledge of epilepsy indicated less stigma concerning people with epilepsy in both groups.

Further analysis using the Linear Regression showed that in the UK group, knowledge is a positive significant predictor of stigma, $F_{(1,114)}$= 9.27, p<.003, R^2=

.075. This result also resonated with the Kurdish group, F $(_{1,198})$ = 9.79, p<.002, R^2= .047.

The data was then compared between the groups for the measures used. The stigma scale scores were first looked at and the results showed that there was no significant difference between the two groups, the UK and Kurdistan. The knowledge of epilepsy was then looked at to test hypothesis three which predicted a significant difference between the groups. The UK group (*M*=25.83, *SD*=4.02) was compared to the scores from the Kurdish group (*M*=18.61, *SD*=3.25), this was a highly significant result, t=17.40, p<.000, d=1.97. The results demonstrate that people in the Kurdish group have significantly less knowledge of epilepsy compared to those in the UK group; however, although the UK group have better knowledge of epilepsy, this does not appear to have influenced stigma concerning people with the condition. Comparing the scores from both groups for the stigma scale of epilepsy, a significant result was not obtained, indicating that feelings of stigma in regards to people with epilepsy is similar in both the UK and the Kurdish group, regardless of the level of knowledge of epilepsy that is possessed.

7.4.2. Hypothesis Three

It was predicted that people in the Kurdish group had scored higher on the stigma scale of epilepsy compared to those in the UK group. Using an independent sample t-test, it was discovered that this was not a true prediction as there was no significant difference between the groups. The null hypothesis, which states that there is no difference in the level of stigma in regards to people with epilepsy between the UK and Kurdish group, is accepted.

7.5. Subsequent Analysis

As the data was split by group, further analysis using Multivariate General Linear Model was run between the two measures (knowledge of epilepsy and stigma scale of epilepsy).

The knowledge of epilepsy and stigma scale of epilepsy were analysed in relation to the four questions asked of participants comparing the UK and Kurdish group. The first question: ‘Do you know or have known anyone who had epilepsy?’ showed highly significant results for both the UK (F=24.00, p<.000) and the Kurdish (F=12.67, p<.000) group, indicating that those participants specifying that they knew someone with epilepsy scored higher on the knowledge of epilepsy measure. When the same question was analysed in relation to perception of stigma, although in both groups those who said ‘no’ scored higher in the stigma scale, a significant result was not achieved.

When participants were asked ‘Would you object to a person with epilepsy marrying a close relative of yours (brothers, sisters, or child)?’ the results demonstrated that those people indicating that they did not object (indicating a ‘no’ response) tended to have better knowledge of epilepsy in both groups. However, a significant result was only observed amongst the Kurdish group, F=4.61, p<.03. In relation to the stigma scale, those participants stating ‘yes’ they would object, scored higher in the stigma scale in the UK group but did not have a significant result. However, a significant result was observed amongst the Kurdish group, F=5.53, p<.02, indicating ‘no’ they would not object to marriage association to a close relative with a person with epilepsy.

The third question asked ‘Would you object to having any of your (eventual) children associate with a person who sometimes had epileptic seizures in school or in a playground?’ the results showed that in the UK group, participants indicated that ‘no’ they did not object to their children playing with other children with epilepsy, F=4.33, p<.04; however, a significant result was not observed among the Kurdish group. Showing that with better knowledge among the UK group changed their intended behaviour but this was not the case among the Kurdish group. No significant result was found between the stigma scores and participant response to this question in either group, UK or Kurdish group.

The final questions asked ‘Do you think that, in general, persons with epilepsy should be employed at the same jobs as other people?’ a significant result was not observed in either group, the UK or the Kurdish, this was also the case for the stigma scale.

The results were further analysed to check whether education predicted knowledge of epilepsy and stigma for the groups separately. For the UK groups, education did not predict better knowledge of epilepsy or stigma concerning those with the condition. Amongst the Kurdish group, however, better educational attainments positively significantly predicts better knowledge, F $(_{1,194})$ =10.94, $p<.001$, $R^2=.053$, and stigma, F $(_{1,194})$ =7.21, $p<.008$, $R^2= .036$.

7.6. Knowledge of Epilepsy – People with & without Epilepsy

This study has shown that people in the Kurdish group without epilepsy have significantly less knowledge of the condition compared to those in the UK group. This is also apparent between the groups for people with or without epilepsy, as the participants in the UK group reported significantly better knowledge of epilepsy compared to the participants in the Kurdish group. To compare these two groups, it is clear from the results that people in the UK have scored much higher than those living in Kurdistan. Those in the UK have better overall scores in both groups, with epilepsy (*M*= 27.71, *SD*= 2.77) and those without epilepsy (*M*= 25.83, *SD*= 4.02) compared to those living in Kurdistan with epilepsy (*M*= 18.22, *SD*= 2.68) and those without the condition (*M*= 18.61, *SD*= 3.25).

7.7. Discussion

This study set out exploring the association of knowledge of epilepsy and stigma scale of epilepsy among the general population. The two variables were first correlated to identify any associations there may exist. This showed that stigma had a strong negative correlation with knowledge of epilepsy, and knowledge of epilepsy was also was a positive significant predictor of stigma. These results indicate that greater stigma concerning people with epilepsy is linked with less knowledge of the condition amongst the general population. This is in line with a number of reported literature that demonstrates that stigma is associated with lack of knowledge Tekle-Haimanot et al., 1991; Doughty et al., 2003).

The analysis then looked at the questions put to the participants at the start of the questionnaire, enquiring about whether they knew or had known someone with epilepsy and whether they would object to future associations. The results showed that knowing someone with epilepsy can have a significant effect on knowledge of the condition and how stigmatised people feel in regards to others with epilepsy. It was also shown that people with better knowledge of epilepsy did not object to a close member of their family to marry a person with the condition. Participants with better knowledge of epilepsy also indicated that they would not object to their children (or eventual children) to play with a child with epilepsy, and when participants were prompted, they also stated that people with epilepsy should be employed in the same jobs as other people. These results were all highly significant and demonstrate that better knowledge of epilepsy affected perception of others in society, and studies have shown this can have a knock on effect on people with the condition (Jacoby & Austin, 2007; Fernandes et al. 2008; Hosseini et al., 2010; WHO, 2010).

The data was then split by group, the UK and Kurdistan, and further analysis carried out. The results showed that stigma was negatively correlated with knowledge of epilepsy in both groups separately; and knowledge showed to be a significant predictor of stigma. This demonstrates that people with better knowledge of epilepsy indicated less stigma concerning people with the condition in the UK and Kurdish group. This was an expected result as lack of knowledge of epilepsy has previously been linked with greater level of stigma in regards to those with the condition (Shehata & Mahran, 2011, Abdulla, 2014). The data were then compared for the scores between the groups. The analysis showed that people in the UK group had significantly better knowledge of epilepsy compared to those in the Kurdish group. This proved to be a significant result, and previous research has shown that people from the UK possess good knowledge of epilepsy (Doughty et al., 2003). A study reported from Kurdistan, in Northern Iraq, has highlighted the extreme lack of knowledge regarding epilepsy amongst primary school head teachers where participants believed that children with epilepsy should be taught in separate classes and stated that those with epilepsy should not take part in physical exercise (Abdulla, 2014). Similar findings were reported from a Turkish study where teachers felt pupils with epilepsy should be taught in separate classes (Aydin & Yildiz, 2007).

The groups were also compared for the stigma scale of epilepsy and the results indicated that there was no significant difference between the two groups. This is an unexpected result as the UK population have shown to possess good knowledge of epilepsy and have less stigma concerning those with the condition (Doughty et al., 2003) compared to those in the Kurdish group. Literature has shown that knowledge is poor in these regions, which is understood to lead to stigma concerning epilepsy and those with the condition (WHO, 2010; Abdulla, 2014). It is reported that stigma differs depending on where in the world people live, and the findings of this study have further supported this (Jacoby & Austin, 2007; Shehata & Mahran, 2011). This result also indicate that although in the UK people are aware of conditions, such as diabetes, asthma, epilepsy and cancer, their knowledge may not be in-depth enough to affect the perception of stigma.

This study did not set out to test any particular theory; however, it has come out in support of relevant theories in the field. The *socio-cultural perspective* (Jones et al., 1984) is a model to explain how people can negatively stereotype others with characteristics that may deviate from the norm. This model suggests that the experiences from the society that individuals inhabit, including information from our parents and the media, affects how perceptions are formed regarding stigmatising condition, such as epilepsy. This theory further suggests that limited exposure and incorrect information can result in conclusions that may be unaccepting of people with stigmatising conditions (Jones et al., 1984). This theory may explain the amount of knowledge that participants in the Kurdish group have about epilepsy and how negative attitudes towards those with the condition are formed.

The groups were then compared on their responses to the questions of knowing and associating with someone with epilepsy. It was found that both groups had better knowledge when they had indicated they had personal knowledge of others with the condition, these were significant results. When participants were asked if they would object to a person with epilepsy and a future marriage association to a close relative, the UK group showed that with better knowledge, they did not object to marriage association. However, in the Kurdish group even with better knowledge of epilepsy, participants indicated they still objected to marriage association with someone with epilepsy, these results were both significant in their direction.

This study raises questions as to the reasons why knowledge does not appear to have a significant effect on stigma but affects the responses of participants when it comes to marriage to a close relative among the Kurdish group. This is in line with studies that report that most people may have heard about a condition but may not possess adequate information regarding the condition (Mecarelli et al., 2007). This result resonates with a study carried out in Iran, where although participants had positive attitudes towards those with epilepsy, they objected to association by marriage with someone with the condition (Masoudnia, 2009; Ghanean et al., 2013). This is similar to findings reported from Turkey (Demirci et al., 2007). There is a possibility that the prospect of epilepsy having a genetic link may cause concern amongst the general population in fear of the condition being passed on to future generations (WHO, 2010). A Brazilian study showed that better knowledge and familiarity about epilepsy as a neurological condition, were associated with higher socio-economic status, however, this was not observed to positively influence attitudes as associations by marriage was still objected by participants (Santos et al., 1998). The results of the present study may be to do the question of hereditary in epilepsy, as found in a Chinese study where there were gaps in knowledge, especially when it comes to the genetic and hereditary factors (Snape et al., 2009). So the reasons for people without epilepsy not wanting a member of their close family associating with someone with epilepsy by marriage may be due to the questions of genetically passing on this condition.

Goffman's (1969) proposal of how individual identities are formed and maintained according to how we want others to identify us, is affected by how others perceive us in society, can be associated with the results of this study. The results showing that even with better knowledge about epilepsy, others' future intentions are negative, in that participants from the Kurdish group objected future associations. This could be related back to what Goffman (1963) called 'spoiled interactions'. In order for others to maintain their own identity in their society, they may not want to be associated with a discreditable or disgraceful condition, or indeed, the discredited or disgraced by other members of society. This is one of the issues that appear to surround those with epilepsy. Although, the results did show that most people would not object to others with epilepsy to be employed at the same jobs as themselves, this could be that the level of stigma is different according to situations. Just as Goffman argues that people can play different characters according to different situations, such as work, home, and social settings, having a close relation to a person with a discreditable condition may not be desirable and could jeopardise own identity in that given society. Having a work relation may not have a great impact on the identity of an individual, however, having personal associations with others with epilepsy, could affect how they could be viewed by others.

This gap in knowledge and misconceptions about epilepsy may be the reason that a study in India has shown that 55% of participants concealed their epilepsy in fear of marriage arrangement breakup (Santosh et al., 2007). This was shown among the qualitative study (chapter five) that those with epilepsy in the UK tend to disclose their condition to those close to them while participants in the Kurdish group conceal their condition from others in fear of repercussions as a result. Contradictory to this a study has been presented by Young et al. (2002) showing that among Canadian college students 95% of their sample would not object to marriage by a close relative to a person with epilepsy.

In the present study, when participants were asked if they would allow their children to play with other children with epilepsy, those in the UK group with better knowledge of epilepsy did not object to this, however, a significant result was not obtained for the Kurdish group. This study has so far shown the difference between the two groups in that with better knowledge of epilepsy those in the UK group have a positive intended outcome towards people with epilepsy, however, this has not been observed among the Kurdish group. Significant results were not found when asked about employment in any of the groups, whether people with epilepsy should be employed at the same jobs as others without epilepsy. This may be due to the nature of the jobs that participants may have felt dangerous for the symptoms experienced by those with epilepsy, as some symptoms of epilepsy can be unpredictable (Chadwick & Usiskin, 1992).

Educational status has been highly linked with the amount of knowledge participants have on epilepsy (Rafael et al., 2010) and the amount of stigma (Doughty et al., 2003) they have towards people with the condition. This study has shown that educational attainments was a significant positive predictor of knowledge of epilepsy and stigma amongst the groups collectively (the UK and Kurdistan together) and also the Kurdish group separately but not amongst the UK group.

The scores from the stigma scale were compared between the two groups, the UK and Kurdistan. In both groups the responses from participants showed that those who did not know someone with epilepsy had higher scores on the stigma measure used in the study. However, there was no significant difference between the UK and Kurdish groups in their responses to having known someone with epilepsy and stigma concerning a person with the condition. Among the UK group, a significant result was not achieved when referring to marriage association even with a high score on stigma, showing that even when people in the UK feel stigmatised in regards to others with epilepsy, this did not affect their objection for future marriage of a close relative to a person with the condition. This cannot be said for the Kurdish group, as those who had higher stigma perceptions of people with epilepsy felt that they would object to a person with epilepsy marrying someone close to themselves, this was a significant result. This may be better explained by other studies (Jacoby &

Austin, 2007; Shehata & Mahran, 2011; & Fernandes et al, 2008) stating that where a person lives in the world and the society they are part of will affect the level of stigma they have in regards to others with epilepsy.

The results of this study have shown that there is a clear divide between the UK and Kurdistan groups and the level knowledge participants reported to have about epilepsy, although stigma was just as high in both sets of data. It appears that knowledge also affects the intended future decisions made by those in the UK and Kurdistan in different ways. While those in the UK group who had better knowledge of epilepsy appear to show positive intended action when it comes to future associations, better knowledge does not equate to a more positive outcome among the Kurdish group. It is also important to note that being educated has been linked with better general understanding of epilepsy, and this was shown in this study. Another important factor is that this study has demonstrated that where a person lives in the world affects intended behaviour, it may be that education about stigmatising conditions are needed in order to reduce that stigma concerning those with epilepsy.

This study was not without its limitations. The questionnaires used for this study were not standardised to use in Kurdistan and all materials had to be translated and back translated, which raises some issues (see chapter five, sub-section 5.3). Another limitation is relating to the Knowledge of Epilepsy measure, in which item 20 has been questioned for its accuracy (see chapter six, sub-section 6.5). Just as discussed in previous chapters, research is quite a new development is Kurdistan, this may have affected participant responses, however, the implications are unknown at this stage.

Chapter 8: General Discussion & Conclusion

This chapter combines the discussions from all three studies and compares the outcomes in relation to published literature.

It is ironic that the first published explanations of epilepsy, as a medical condition, were recorded in Iraq (historically Babylon or Mesopotamia) some 4000 years ago, not far from where data for this research was collected. In current times, however, it appears that this region of the world lacks in reported literature about epilepsy as a neurological condition and the effects of diagnosis on a person (Seidenberg et al. 2004; Raggi et al., 2015). Epilepsy is a complex condition and although medical understanding of this chronic condition has advanced (Kelso & Cock, 2004), considering the length of time the origins of epilepsy is known and the work that has been directed in this area, it is still a somewhat mysterious condition, especially for those in the developing countries (WHO, 2010). This is mainly due to the many varieties of epilepsy and numerous types of symptoms associated with epilepsy (ILAE, 2014). This research has added to and confirmed some literature reports regarding epilepsy.

The first study, a qualitative investigation into the lives of people with epilepsy (chapter five) highlighted some similarities and differences between the UK and Kurdistan group. The UK participants appeared much more knowledgeable about their condition and the restrictions placed upon them as a direct result of their diagnosis. This positive outlook could be associated with the support of the medical profession and the level of knowledge participants were equipped with, such as knowing the cause and origin of their condition, and the triggers and symptoms to look out for. Adequate medical support and self-awareness appeared to further aid better coping and adjustment to their epilepsy among the UK group. Additionally, another positive factor was the level of perceived control some participants from the UK group felt they possessed over their symptoms, for example, having a healthy lifestyle and getting adequate rest.

In contrast, acceptance and coping with epilepsy amongst the Kurdish group came from religious and spiritual beliefs in ‘God’ as it has previously been reported in this area (Ismail et al., 2005). It has been found that people from a Muslim background in the UK also believe that it was God’s will that they had epilepsy and acceptance appeared to come from the comfort of that thought process (Ismail et al., 2005). This relates to this present research, where ‘God’ was referred to during the interviews (chapter five) when enquiring about causations and coping. It appears that among the Kurdistan group participants would state that they had no choice but to accept their condition as it was from ‘God’, however, this does not mean to say that they had dealt with the psychological issues of having a chronic neurological condition, only that they had no other explanations for having epilepsy. Current literature has highlighted religion as a source of active coping mechanism where people have been diagnosed with a serious health condition such as epilepsy (Cummings & Pargament, 2010). Further research is recommended to highlight whether religion has helped those with epilepsy in Kurdistan cope with their diagnosis by using Psychological Measures of Islamic Religiousness. This measure enquires to the extend religion helps in their coping mechanisms (Abu Raiya, Pargament, Mahoney, & Stein, 2008). Another factor contributing to the acceptance from a spiritual entity may be due to the absence of investigative tools in the developing countries (Birbeck, 2010) which may also be linked with the lack of knowledge in these regions of the world.

Perceived lack of control over seizures is known to impact people with epilepsy even with periods of seizure freedom and has been linked with quality of life (Jacoby, 1992; Baker et al., 1997; Krakow, Bühler, & Haltenhof, 1999; Ahmad, 2011). The lack of control over seizures is a hindrance and a source of worry for many people with epilepsy and was highlighted in the qualitative study (chapter five) amongst all people with epilepsy, especially those in the Kurdish group.

As a result of this study (chapter five) it is proposed that the anticipation of stigma is associated with participants in the Kurdistan group choosing to conceal their condition rather than be open with those around them (Kleck, et al., 1968; Schnieder & Conrad, 1980; Joachim & Acorn, 2000). In other studies, it has been suggested that disclosure among some German participants were more likely to take place if they felt that a seizure would occur and give them away or they anticipated a supportive social environment (Tröster, 1997). Among the participants in the Kurdish group, social support outside of the immediate family was not available to those with epilepsy. Furthermore, as epilepsy may have negative connotations attached to it, it is unlikely that a Kurdish person with epilepsy will disclose their condition willingly to anyone outside the comfort of their immediate family, as it has been found in previous studies carried out in Middle-East (Good, 1994; Baker et l., 2005; WHO, 2010; Ahmad, 2011).

Among the Kurdish group, epilepsy appeared to define the person with the condition, and affected their lives in regards to work, friendship and marriage. It appears that better knowledge of epilepsy could lead to some of the misconceptions about this condition, which can lead to stigma, disintegrate by arming those with the condition to have a more positive outlook on their future. This could affect better coping and adjustment to epilepsy. Furthermore, it appeared that people with epilepsy felt devalued because of their condition, due to the views held in that region about epilepsy. A person with epilepsy in the Kurdistan region is not ‘normal’, and people with the condition and their families are undervalued. This is where Goffman’s ‘spoiled interaction’ can be used to explain the types of behaviour reported by the Kurdish participants. This was shown to have a negative effect on the life of a person with epilepsy in regards to the stigma they felt and the support they received outside the immediate family. This could be associated with the lack of knowledge people have about epilepsy or the absence of literature in this area, which has not helped advance the support available for those with epilepsy. Stigma can have a negative impact and has been linked with the quality of life of people with epilepsy (Whatley et al., 2010; Ahmad, 2011).

Descriptions of *felt* and *enacted* stigma were given by the UK and Kurdish participants, but in different ways (Scambler & Hopkins, 1990; Scambler, 1993; Jacoby & Austin, 2007). Among the UK group, reports of *enacted* stigma, especially institutionalised stigma, were raised where the restrictions on driving and employment affected them (Jacoby and Austin, 2007). However, the stigma reported by the participants in the Kurdistan group related to social acceptance and their position in their community. This could affect education and marriage prospects for those with epilepsy in Kurdistan (Ahmad, 2011). More Kurdish participants referred to *felt* stigma, and this type has been reported to be more distressing for the individual (Scambler & Hopkins, 1990; Scambler, 1993; Jacoby & Austin, 2007). The types of stigma as described by those in the Kurdistan group could further be linked with the *negative attributes model* (Katz, 1981). This model suggests that people may be stigmatised by others in their society if they are perceived to have negative or undesirable traits or characteristics.

The second study (chapter 6) of people with epilepsy (quantitative method) showed another dimension of the experiences of people with the condition. Depression is one of the impacts of an epilepsy diagnosis (Ramaratnam et al., 2008; Mehndiratta & Sajatovic, 2013; Drinovac et al., 2015; Micoulaud-Franchi et al., 2015) and has been found to negatively influence quality of life (Boylan et al., 2004; Tedrus et al., 2013; Drinovac et al., 2015; Micoulaud-Franchi et al., 2015). Studies have shown that depression is a strong predictor of quality of life in people with epilepsy (Seidenberg et al. 2004; Raggi et al., 2015); furthermore, depression has also been found to be a significant predictor of suicide in people with epilepsy (Hecimovic et al., 2012). From this research it is clear that depression exists among people with epilepsy, especially in the Kurdistan group. Similarities between the UK and the Kurdistan groups were apparent where depression strongly predicted quality of life amongst all people with epilepsy, collectively and separated by group.

Further findings as a result of this research showed that amongst people with epilepsy, reported symptoms of depression significantly correlated with seizure severity and knowledge of epilepsy. Indicating that the less knowledgeable the participants reported they were about their condition the more depressed they reported to be, also the more severe the reported seizures the more depressed participants stated being. This study further highlighted that the more depressed the participants reported being, the more serious they felt their condition was, this resonated among the UK and Kurdish groups separately as well as a whole group.

This study has highlighted that people with epilepsy in the UK have a significantly better quality of life compared to those in the Kurdistan group, resonating with literature reports showing that quality of life is compromised for those with epilepsy in culturally bound societies where lack of knowledge is also a factor (Mrabet, Mrabet, Zouari, & Ghachem, 2004; Ahmad, 2011; Tedrus et al., 2013; Abdulla, 2014). Poorer quality of life, in the developing countries, has been associated with lower employment (Bahou, Jaber & Kasasbeh, 2011), fewer marriage prospects (Amir et al., 1999) and anticipation of stigma (Ahmad, 2011). The restrictions to advancements in health care and technologies, together with religious and individuals' restrictions have a detrimental effect on quality of life in people with epilepsy (WHO, 2003; Scott at al., 2001); similar impacts could be associated with Kurdistan.

The study of people with epilepsy (chapter 6) highlighted the variables that significantly predict quality of life. For this group, the results demonstrated that quality of life is affected by where in the world a person lives (WHO, 2010; Fernandes et al. 2008). Quality of life was shown to be significantly better for those with epilepsy living in a developed country such as the UK compared to those living in a developing area of the world, Kurdistan. It was also clear that among the UK participants perceived illness seriousness, depression and perceived stigma negatively correlated with quality of life using Pearson's correlation. These same significant correlations were also observed among the Kurdistan group. However, significant predictors of quality of life among the UK group were perceived illness seriousness and depression. These variables have a significant negative impact on quality of life of a person in the UK with epilepsy. Also, further analysis highlighted that depression mediated the effects of perceived stigma, which was also a significant predictor.

Just as observed amongst the UK group, the results from the Kurdish group also showed that perceived stigma did not have a direct negative influence on quality of life. However, perceived stigma, with depression as a mediating variable, indirectly and negatively influenced the quality of life of people with epilepsy amongst the participants in both groups with epilepsy. These results are crucial in that it is the first of its kind to look at these two groups and will also provide to be a great foundation for future research.

Among the Kurdistan group it was observed that the best predictors of quality of life were depression and seizure severity. The more depressive symptoms a person with epilepsy reports in Kurdistan, the more likely this will negatively affect their quality of life. An unexpected result was observed among the Kurdish group where seizure severity was concerned. The results showed that reports of more severe seizures by the participants, resulted in better quality of life, this contradicts other studies in this area (Harden et al., 2007; Bautista & Glen, 2009; Sancho et al., 2010; Milovanović et al., 2014). This unexpected result could be down to a number of factors. This region in Middle-East is not researched often and filling in questionnaires are a new exercise which could have affected how participants selected their choices. Another possible explanation could be down to the support that is provided by the families of those with epilepsy. That having severe seizures could impact on more support given to the person with epilepsy which could lead to a better reported quality of life of those with the condition. Another explanation could be that due to the nature of epilepsy, it is difficult for those experiencing a seizure to be aware of how severe they are when the person experiencing the episodes is sometimes unconscious (WHO, 2010; ILAE, 2014). Also, it could be that the measure used for this research was not suitable and the participants could not relate to it. A final possible explanation for the unexpected result is that participants may have experienced the Hello-Goodbye effect (Choi & Pak, 2007). This is where participants may have felt that they would need to exaggerate their seizure severity in order to take part in the study. This result needs further exploration to investigate the reasons for this unexpected outcome from the Kurdistan group.

The final study as part of this research was that of people without epilepsy (chapter 7). The results showed that knowledge of epilepsy is significantly correlated with stigma concerning people with the condition in the UK and Kurdistan group, and is significant predictor for stigma. This is in line with the literature suggesting that better knowledge of epilepsy can have a positive influence on the level of stigma others feel in regards to those with the condition (Shehata & Mahran, 2011). The results further highlighted that participants in the UK group demonstrated a significantly better knowledge of epilepsy compared to those in the Kurdistan group. These results confirm findings that suggest the UK population have a good knowledge of epilepsy (Doughty et al., 2003) and that Kurdistan is lacking in knowledge of the condition (Abdulla, 2014). However, although stigma concerning people with epilepsy was higher in Kurdistan compared to the UK, this was not a significant difference.

The results also showed that with better knowledge of epilepsy, people in the UK do not object to a close relative marrying someone with epilepsy, however, in the Kurdistan group, participants still objected to marriage association with a person with epilepsy. This is in line with studies carried out in neighbouring Iran (Masoudnia, 2009; Ghanean et al., 2013), and Turkey (Demirci et al., 2007). This could be explained by the genetic associations of epilepsy (WHO, 2010), that people are worried that epilepsy can be genetically inherited and affect future generations. This could also be down to the society people belong to. Epilepsy is potentially a disgraceful condition and others may not want to be closely associated with others who are not respected in society in fear of ‘spoiled interaction’ (Goffman, 1963). It may be this negative attitude that hinders people with epilepsy to disclose their condition from others in Kurdistan, as this could affect the lives of those with the condition, in circumstances such as education (Ahmad, 2011) and marriage prospects (Santosh et al., 2007).

Education has previously been associated with the level of knowledge people have and the amount of stigma they feel concerning those with the condition (Rafael et al., 2010). The present study (chapter 7) confirmed this by showing that higher educational attainments were associated with the level of knowledge and how much stigma they felt in regards to those with the condition. This study, like others, has shown that there is a clear divide on the level of knowledge a person has about epilepsy depending on which part of the world they live in (Jacoby & Austin, 2007; Fernandes et al, 2008; Shehata & Mahran, 2011). Although, the UK has shown to have significantly more knowledge of epilepsy compared to Kurdistan, this was not matched by a significantly less stigma concerning those with the condition.

The results of this research can add to quality of life theories, in that more attention needs to be paid to its symptoms and the management of epilepsy. The quality of life in epilepsy appears to be influenced by psychosocial factors, such as depression (chapter 6), adjustment and coping (chapter five), and also societal factors such as stigma (chapters five & six). The severity of the seizures itself, appear to be insignificant where the quality of life of someone with epilepsy is concerned, it may be more the inconsistency and frequency of the episodes that negatively influence those with the condition. It is proposed, as a result of this research, that quality of life theories in epilepsy include the impacts of the symptoms of the condition, available treatment, psychosocial measures and cultural or societal considerations, as well as perceived control over the symptoms. An addition to the WHO (2003) International Classification of Functioning, Disability and Health (ICF) to include epilepsy and its associated issues, such as stigma, symptoms and treatments, would be suggested as this model also includes social, political and environmental impacts on quality of life.

The concept of individualism and collectivism as presented by Hofstede (1980) could be applied to some aspects of the findings of this research. The collective characteristics of the two cultures appear to be significant in influencing the differences observed between the measures used. There appears to be a significant difference between the level of knowledge about epilepsy between the two cultures, as well as perceived and reported stigma which could influence the reported quality of life of people with the condition. Furthermore, the observations made in chapter five in relation to stigma and concealing or disclosing of an epilepsy diagnosis could be influenced by factors in the individualism/collectivism characteristics. The Kurdish participants, belonging to a collectivist society, were hesitant to disclose their condition, and according to this concept, could be influenced by protecting the family from negative association made by others as a result. This could also be true in cases of men with epilepsy in Kurdistan as they are expected to be strong and cannot be seen to be weak.

Amongst the UK participants, belonging to an individualistic culture, the differences were also apparent. In this type of society, where individual's connections are 'loose', individuals believe in their own dignity. Participants with epilepsy (chapter five) were comfortable with disclosing their epilepsy to those around them. This could be associated with members of society being exposed to more information about epilepsy and the power distance between individuals in society.

Whilst the above concept is useful for recognising the differences between cultures, it has also received numerous criticisms in regards to the assumptions made by the model. The classification of individualism/collectivism dichotomy as proposed by Hofstede (1980) is the process of collective characteristics of different societies and does not explain behaviour at an individual level (Oyserman, Coon, & Kemmelmeier, 2002). Assuming the individualism/collectivism assessment is relevant at an individual level, is one of the drawbacks of applying Hofstede’s method (Oyserman et al., 2002). This method further suggests that the classifications of individualism/collectivism and its application for different cultures are stable over time, which may not be the case as the wealth of a country could be subject to change which, according to this concept, precedes individualism (Oyserman et al., 2002). It further assumes the individualistic perspective from the American European research to be an adequate model of behaviour for application to other countries, this is arguable as belonging to the same category of individualism/collectivism does not imply that the meaning of values are consistent across all societies for all individuals (Gouveia & Ros, 2000). It is also important to state that using Hofstede’s (1980) measure is a rigid process and presumes that individualism and collectivism are on the opposite sides of the same spectrum where a country or society belongs to one or the other (Oyserman et al., 2002). This concept suggests that if a society is high in collectivist values then they must be low in individualism traits (Oyserman et al., 2002).

The individualism/collectivism assumption is that individualistic members of society are self serving and are more interested in achieving personal goals compared to collectivist members of society where they are devoted to their group or community progression (Schwartz, 1990). It could be that societies could share some cultural values and still belong to either a collectivist or individualistic society; however, Hofstede’s concept does not give freedom for this proposal (Oyserman et al., 2002). Viewing individualism/collectivism as being in conflict overlooks the similarities they share (Schwartz, 1990). Values that are important to individuals, such as wisdom or knowledge, could exist in both individualistic and collectivist societies as it can serve both personal and group growth (Schwartz, 1990). Additionally, there may be values that could serve collective goals amongst individuals in all societies, such as equality and preserving nature (Schwartz, 1990).

Whilst the individualism/collectivism model is an informative tool to guide researchers of collective characteristics of different societies, behaviours of its members from an individual standpoint should not be assumed (Oyserman et al., 2002). It should also be noted that the individualism criteria is based on how American individuals view themselves and this may not be applicable if taken out of context and applied to individuals from other cultures (Oyserman et al., 2002).

The results of this research have shown that quality of life is indeed affected by where in the world a person lives (Fernandes et al, 2008; WHO, 2010). Living in a developed society with better knowledge of conditions, such as epilepsy, has a significant positive effect on the reported overall quality of life, compared with living in a developing region. This is also matched by the high levels of perceived and anticipated stigma due to the nature of epilepsy and the fear of being a 'discredited' member of society (Goffman, 1963). Goffman's concept of stigma is valid still and has been resurrected once more, based on the results of this research. The theory of the 'discreditable' and 'discredited' is also very relevant in this study, as is the notion of 'spoiled interaction' (Goffman, 1963, 1969). A possible addition, based on these results, would be that within the different types of stigma, Goffman has presented, there are possibly levels of acceptance or discreditation by others. An individual may be fully discredited or disgraced if they have the potential to be a close member of their family and have, a possible, direct impact on others but not discredited fully if having to only work with those with stigmatising characteristics, in which case it is an indirect influence.

There is a high level of reported depression among people with epilepsy, which appears to be affected by the symptoms of the condition, the environment individuals belong to and their prospects (Beck, 2002). Future prospects for those with epilepsy appears grim, according to the findings of this research, due to the anticipated stigma, uncertainty of seizure occurrences, reported depressive symptoms and the seriousness of the condition itself. All these factors impact negatively on the outcome of quality of life. With a diagnosis of a serious chronic condition, such as epilepsy, it is highly recommended that diagnosing this condition be matched by support and education to guide acceptance and management by those directly affected by epilepsy. It has been previously reported that social support has a positive influence on illnesses management (Gallant, 2003). Furthermore, better support has been found to have a positive effect on the sense of mastery among those with epilepsy (Amire, et al, 1999).

This research was not without its limitations. One of the main negative points associated with this research, and in particular the qualitative study, is the issue surrounding data collected in a different language. Interview data had to be translated into English, which can be questioned for its rigorousness as it is not standard practice, as yet, to translate and back translate interview material (Chen & Boore, 2010). The contents of the interviews of the qualitative study were not back translated, which may have led to essential data being lost in translation (Jagosh & Boudreau, 2009; Chen & Boore, 2010). There does not appear to be any set standards for qualitative researchers to follow as a guide for producing data in a different language to English, however, there is a rise in literature highlighting this very issue (Jagosh & Boudreau, 2009; Chen & Boore, 2010). Additionally, it has been suggested that further understanding of translation, back translation and transliteration is much needed in order for social health research to advance. This is due to qualitative research methods being used much more in health related studies (Jagosh & Boudreau, 2009; Regmi, Naidoo, & Pilkington, 2010; Chen & Boore, 2010). Bearing this limitation in mind, it is also reported that although the exact wording of translations may not be in the same place, the meaning and the essence of an interview can still be captured by the translation of the data into a different language (Wong & Poon, 2010).

Another factor that may have influenced the qualitative study outcome further is that amongst the UK group, nine out of the ten participants were recruited from an epilepsy conference held for those with the condition in the UK. This may have affected the results in that people with epilepsy attending this conference may have a better understanding and awareness of their condition. Furthermore, the conference appeared to be a support network for those with epilepsy, this is far more than what was available to those with epilepsy in Kurdistan. This could have influenced the outcome of this study, however, to what degree, it is unknown.

A further limitation of this research is that, although every care was taken in translating and back translating the quantitative questionnaires, they have not gone through the rigorous testing to ensure they are standardised to use in the Kurdish language, which may have had an unknown effect.

From the research it is clear that there is a distinction in how the UK and the Kurdistan group have differed in their response to an epilepsy diagnosis. Stigma plays a fundamental role in the quality of life of a person with this condition and many variables contribute to this outcome. The results of this research has shown that knowledge of epilepsy is significantly better in the UK as a developed country, however, knowledge of this condition is somewhat lacking in Kurdistan, northern Iraq, as a developing region. This lack of knowledge of epilepsy leads to high levels of perceived stigma and negatively affects quality of life in those with the condition. It is recommended that more care should be taken when diagnosing an epileptic condition. This care is critical as the medical profession may be diagnosing someone who is originally from a developing country where there still remain high levels of misconceptions. However, this could be just as important for someone from the UK as this could lead to problems of acceptance for the patient and their family. This could depend on how their community perceive epilepsy. It has been suggested that support groups may be helpful for people with epilepsy to help them accept and manage their condition better (Amir et al., 1999).

In Kurdistan, Northern Iraq, epilepsy is poorly understood and there is limited support for a person with epilepsy outside of their familial support network. This has led to significant stigma experienced by those with the condition from the society live in, which affects their life considerably. The findings of this research will be presented to the local government and regional policy makers for better provision for those diagnosed with epilepsy.

It is recommended that work on the impact of an epilepsy diagnosis is highlighted further, especially in less developed regions, in order for better quality of life to be achieved for people with epilepsy. It appears that support is needed for those with epilepsy to ensure they are equipped with the correct and adequate knowledge in order to be able to adjust and cope with their epilepsy. Awareness is also needed for the general public as negative attitudes from the general public can have a negative influence on the stigma experienced by those with epilepsy. Furthermore, support is needed to ensure that depressive symptoms are recognised in people with epilepsy and treated with the correct therapy. As a result of this research, it is proposed that these recommendations collectively may have a positive influence on the quality of life of people with epilepsy in the UK and Kurdistan.

In conclusion, this was an essential research and can be a firm foundation for further research in this area. This research is the first of its kind and will go a long way towards knowledge about epilepsy and the support needed to improve people's quality of life. Perceived stigma and stigma concerning those with the condition have been highlighted across both groups; however, felt stigma was more prevalent amongst the Kurdish group. Knowledge could also be directed at those without epilepsy as this has a great impact on how people with the condition are treated in society. Additional research is much needed to further explore the findings of the current studies, such as the reason for seizure severity positively predicting quality of life amongst Kurdish people with epilepsy, and to further the academic literature and to provide a firm foundation for growth of knowledge in this field.

Chapter 9: References

Aalbers, M., Vles, J., Klinkenberg, S., Hoogland, G., Majoie, M., & Rijkers, K. (2011). Animal models for vagus nerve stimulation in epilepsy. *Experimental Neurology*, *230*(2), 167-175.

Abdulla, S. A. (2014). Primary School Managers' Knowledge of and Attitude towards Epilepsy among Children in Erbil City, Iraq. *Sultan Qaboos University medical journal*, *14*(2), e218.

Abu Raiya, H., Pargament, K. I., Mahoney, A., & Stein, C. (2008). A psychological measure of Islamic religiousness: Development and evidence for reliability and validity. *The International Journal for the Psychology of Religion*, *18*(4), 291-315.

Adorno, T. W. (1950). *The authoritarian personality*. New York: Harper & Row.

Ahmad, M. (2011). Epilepsy: Stigma and Management. *Current Research in Neuroscience* **1** (1): 1-14.

Alanis-Guevara, I., Pena, E., Corona, T., Lopez-Ayala, T., Lopez-Meza, E., & Lopez-Gomez, M. (2005). Sleep disturbances, socioeconomic status, and seizure control as main predictors of quality of life in epilepsy. *Epilepsy & Behavior*, *7*(3), 481-485.

Al-Eryani, B., Saied, K. G., Sharaf Alddin, R., Al-Sobaihi, S., Lutf, W., & Al-Taiar, A. (2015). Knowledge of, attitudes toward, and perceptions of epilepsy among university students in yemen. *Epilepsy and Behavior, 52*, 102-107.

Al-Jawadi, A. A., & Abdul-Rhman, S. (2007). Prevalence of childhood and early adolescence mental disorders among children attending primary health care centers in Mosul, Iraq: a cross-sectional study. *BMC Public Health*, *7*(1), 274.

Amir, M., Roziner, I., Knoll, A., & Neufeld, M. Y. (1999). Self-Efficacy and social Support as Mediators in the Relation Between Disease Severity and Quality of Life in Patients with Epilepsy. *Epilepsia*, **40** (2), 216-224.

Angus-Leppan, H. (2008). Diagnosing epilepsy in neurology clinics: a prospective study. *Seizure*, *17*(5), 431-436.

Asadi-Pooya, A. A. (2005). Drug compliance of children and adolescents with epilepsy. *Seizure*, *14*(6), 393-395.

Atkinson, R., & Flint, J. (2001). Accessing hidden and hard-to-reach populations: Snowball research strategies. *Social research update*, *33*(1), 1-4.

Aydin, K., & Yildiz, H. (2007). Teachers’ perceptions in central Turkey concerning epilepsy and asthma and the short-term effect of a brief education on the perception of epilepsy. *Epilepsy & Behavior*, *10*(2), 286-290.

Bahou, Y. G., Jaber, M. S., & Kasasbeh, A. S. (2011). Quality of life in epilepsy at Jordan University Hospital. *Neurosciences (Riyadh)*, *16*(1), 18-23.

Bakas, T., McLennon, S. M., Carpenter, J. S., Buelow, J. M., Otte, J. L., Hanna, K. M., ... & Welch, J. L. (2012). Systematic review of health-related quality of life models. *Health Qual Life Outcomes*, *10*(1), 134.

Baker, G. A. (2001). Assessment of quality of life in people with epilepsy: some practical implications. *Epilepsia*, *42*(s3), 66-69.

Baker, G. A. (2002). People with epilepsy: what do they know and understand, and how does this contribute to their perceived level of stigma?. *Epilepsy & Behavior*, *3*(6), 26-32.

Baker, G. A. (2002). The psychosocial burden of epilepsy. *Epilepsia*, *43*(s6), 26-30.

Baker, G. A., Jacoby, A., Buck, D., Stalgis, C., & Monnet, D. (1997). Quality of life of people with epilepsy: a European study. *Epilepsia*, *38*(3), 353-362.

Baker, G. A., Jacoby, A., Gorry, J., Doughty, J., & Ellina, V. (2005). Quality of life of people with epilepsy in Iran, the Gulf, and Near East. *Epilepsia*, *46*(1), 132-140.

Baker, G. A., Smith, D. F., Dewey, M., Jacoby, A., & Chadwick, D. W. (1993). The initial development of a health-related quality of life model as an outcome measure in epilepsy. *Epilepsy Research*, *16*(1), 65-81.

Ballard, C., Gauthier, S., Corbett, A., Brayne, C., & Aarsland, D. & Jones E (2011) Alzheimer’s disease. *Lancet 377*, 1019-1031.

Baron, R. M., & Kenny, D. A. (1986). The moderator–mediator variable distinction in social psychological research: Conceptual, strategic, and statistical considerations. *Journal of personality and social psychology*, *51*(6), 1173.

Bautista, R. E. D., & Glen, E. T. (2009). Seizure severity is associated with quality of life independent of seizure frequency. *Epilepsy & Behavior*, *16*(2), 325-329.

Bax, M., Goldstein, M., Rosenbaum, P., Leviton, A., Paneth, N., Dan, B., ... & Damiano, D. (2005). Proposed definition and classification of cerebral palsy, April 2005. *Developmental Medicine & Child Neurology*, *47*(08), 571-576.

Bazil, C. W. (2003). Epilepsy and sleep disturbance. *Epilepsy & Behavior* 4 S39–S45.

Beck, A. T. (2002). Cognitive models of depression. *Clinical advances in cognitive psychotherapy: Theory and application*, *14*, 29-61.

Beghi, E. (2004). *Aetiology of epilepsy* (p. 61). Blackwell Science, Oxford.

Beghi, E., Roncolato, M., & Visona, G. (2004). Depression and altered quality of life in women with epilepsy of childbearing age. *Epilepsia*, *45*(1), 64-70.

Benoit, C., & Shumka, L. (2009). What is Stigma. In *Women's Health Research Network Workshop: Challenging Myths and Misperceptions: Working to Reduce Stigma and Enhance Public Understanding of People Who Work in the Sex Industry, Victoria, British Columbia, January* (pp. 16-17).

Bentham, J., & Bowring, J. (1843). *The Works of Jeremy Bentham* (Vol. 7). W. Tait.

Biddle, B. J. (1986). Recent development in role theory. *Annual review of sociology*, 67-92.

Binder, J., Achten, E., Constable, R. ., Detre, J., Gaillard, W., Jack, C., & Loring, D. (2002). Functional MRI in epilepsy.*Epilepsia*, *43*, 51-63.

Binder, M., & Coad, A. (2013). "I'm afraid I have bad news for you…" Estimating the impact of different health impairments on subjective well-being. *Social Science & Medicine*, *87*, 155-167.

Birbeck, G. L. (2010). Epilepsy Care in Developing Countries: Part I of II. *Epilepsy Currents*, *10*(4), 75–79.

Birbeck, G. L., Hays, R. D., Cui, X., & Vickrey, B. G. (2002). Seizure reduction and quality of life improvements in people with epilepsy. *Epilepsia*, *43*(5), 535-538.

Bishop, M. (2005). Quality of life and psychosocial adaptation to chronic illness and disability preliminary analysis of a conceptual and theoretical synthesis.*Rehabilitation Counseling Bulletin*, *48*(4), 219-231.

Bishop, M., & Allen, C. A. (2003). The impact of epilepsy on quality of life: a qualitative analysis. *Epilepsy & Behavior*, *4*(3), 226-233.

Black, G. (1993). *Genocide in Iraq: the Anfal campaign against the Kurds*. Human Rights Watch.

Blumenfeld, H., & Taylor, J. (2003). Why do seizures cause loss of consciousness?. *The Neuroscientist*, *9*(5), 301-310.

Borrell-Carrió, F., Suchman, A. L., & Epstein, R. M. (2004). The biopsychosocial model 25 years later: principles, practice, and scientific inquiry. *The Annals of Family Medicine, 2*(6), 576-582.

Boylan, L. S., Flint, L. A., Labovitz, D. L., Jackson, S. C., Starner, K., & Devinsky, O. (2004). Depression but not seizure frequency predicts quality of life in treatment-resistant epilepsy. *Neurology*, *62*(2), 258-261.

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative research in psychology*, *3*(2), 77-101.

Breakwell, G.M., Hammond, S., & Fif-Schaw, C. (2001). Research Methods in Psychology, Second Edition. Sage Publications.

Brigo, F., Igwe, S. C., Ausserer, H., Tezzon, F., Nardone, R., & Otte, W. M. (2015). Epilepsy-related stigma in European people with epilepsy: Correlations with health system performance and overall quality of life. *Epilepsy & Behavior*, *42*, 18-21.

Brislin, R. W. (1970). Back-Translation for Cross-Cultural Research. *Journal of Cross-Cultural Psychology*, **1** (3), 185-216.

Broadbent, E., Petrie, K. J., Main, J., & Weinman, J. (2006). The brief illness perception questionnaire. *Journal of psychosomatic research*, *60*(6), 631-637.

Brodie, M. J., & French, J. A. (2000). Management of epilepsy in adolescents and adults. *The Lancet*, *356*(9226), 323-329.

Brown, M. T., & Bussell, J. K. (2011). Medication Adherence: WHO Cares? *Mayo Clinic Proceedings*, *86*(4), 304–314.

Camfield, L., & Skevington, S. M. (2008). On subjective well-being and quality of life. *Journal of Health Psychology*, *13*(6), 764-775.

Chadwick, D., & Usiskin, S. (1992). Living with Epilepsy. Optima.

Chaliand, G. (Ed.). (1993). *A people without a country: the Kurds and Kurdistan*. Interlink Books.

Chen, H. Y., & Boore, J. R. (2010). Translation and back-translation in qualitative nursing research: methodological review. *Journal of clinical nursing*,*19*(1-2), 234-239.

Choi, B., & Pak, A. (2007). Hello-Goodbye Effect. In Neil J. Salkind, & K. Rasmussen (Eds.), *Encyclopedia of Measurement and Statistics.* (pp.430-431). Thousand Oaks, CA: Sage Publications, Inc.

Choi, E. J., Lee, S. A., Jo, K. D., Yim, S. B., No, Y. J., Kwon, J. H., & Lee, E. M. (2011). Factors contributing to concerns of persons living with epilepsy.*Seizure*, *20*(1), 14-17.

Choi-Kwon, S., Chung, C., Kim, H., Lee, S., Yoon, S., Kho, H., & Oh, J. (2003). Factors affecting the quality of life in patients with epilepsy in Seoul, South Korea. *Acta Neurologica Scandinavica*, *108*(6), 428-434.

Clark, D. A., & Beck, A. T. (2010). Cognitive theory and therapy of anxiety and depression: convergence with neurobiological findings. *Trends in cognitive sciences*, *14*(9), 418-424.

Clark, S. A., Davies, H., Jenny, M., Glaser, A., & Eiser, C. (2005). Parental Communication and Children's Behaviour Following Diagnosis of Childhood Leukaemia. *Psycho-Oncology*, 14: 274-281.

Cohen, J. (1992). Statistical power analysis. *Current directions in psychological science*, 98-101.

Collings, J. A. (1990). Epilepsy and well-being. *Social Science & Medicine*,*31*(2), 165-170.

Collings, J. A. (1995). The impact of epilepsy on self-perceptions. *Journal of Epilepsy*, *8*(2), 164-171.

Cooley, C. H. H. N., & Nature, H. (1902). the Social Order. *New York: Charles Scribner's Sons*. Cited in Stryker, S., & Statham, A. (1985). Symbplic Interaction and Role Theory. In Lindzey, G. (3rd Ed.). *Handbook of social psychology* (Vol. 1) (pp. 311-378). New York: Random house.

Costanza, R., Fisher, B., Ali, S., Beer, C., Bond, L., Boumans, R., ... & Snapp, R. (2007). Quality of life: An approach integrating opportunities, human needs, and subjective well-being. *Ecological economics*, *61*(2), 267-276.

Cramer, J. A. (2002). Principles of Health-related Quality of Life: Assessment in Clinical Trials. *Epilepsia*, *43*(9), 1084-1095.

Cramer, J. A., Arrigo, C., Van Hammée, G., & Bromfield, E. B. (2000). Comparison between the QOLIE-31 and derived QOLIE-10 in a clinical trial of levetiracetam. *Epilepsy research*, *41*(1), 29-38.

Cramer, J. A., Perrine, K., Devinsky, O., & Meador, K. (1996). A Brief Questionnaire to Screen for Quality of Life in Epilepsy The QOLIE-10.*Epilepsia*, *37*(6), 577-582.

Cramer, J. A., Perrine, K., Devinsky, O., Bryant-Comstock, L., Meador, K., & Hermann, B. (1998). Development and cross-cultural translations of a 31-item quality of life in epilepsy inventory. *Epilepsia*, *39*(1), 81-88.

Cramer, J.A., Perrine, K., Devinsky. O., & Meador. K. (1996). A Brief Questionnaire to Screen for Quality of Life in Epilepsy, The QOLIE-10. *Epilepsia*, **37**(6); 577-582.

Crawshaw, J., & Chambers, J. (2002). A concise course in Advanced Level Statistics with Worked Examples, Fourth Edition. Nelson Thornes Ltd.

Crepin, S., Godet, B., Chassain, B., Preux, P., & Desport, J. (2009). Malnutrition and epilepsy: A two-way relationship.*Clinical Nutrition*, *28*(3), 219-225.

Creswell, J. W. (2009). Research Design: Qualitative, Quantitative, and Mixed Methods Approaches. Printed in the United States of America, *Library of Congress Cataloging-in-Publication Data.*

Creswell, J. W. (2013). *Research design: Qualitative, quantitative, and mixed methods approaches*. Sage publications.

Cummings, J. P., & Pargament, K. I. (2010). Medicine for the spirit: religious coping in individuals with medical conditions. *Religions*, *1*(1), 28-53.

Dagnan, D., & Sandhu, S. (1999). Social comparison, self-esteem and depression in people with intellectual disability. *Journal of Intellectual Disability Research*, *43*(5), 372-379.

De Boer, H. M., Mula, M., & Sander, J. W. (2008). The global burden and stigma of epilepsy. *Epilepsy & Behavior*, *12*(4), 540-546.

de Lau, L. M., & Breteler, M. M. (2006). Epidemiology of Parkinson's disease.*The Lancet Neurology*, *5*(6), 525-535.

Deiner, E., Suh, E., Lucas, R. E., & Smith, H. L. (1999). Subjective well-being: Three decades of progress. *Psychological Bulletin*, *125*(2), 276-302.

Demirci, S., Dönmez, C. M., Gündoğar, D., & Baydar, Ç. L. (2007). Public awareness of, attitudes toward, and understanding of epilepsy in Isparta, Turkey. *Epilepsy & Behavior*, *11*(3), 427-433.

Denzin, N. K., & Lincoln, Y. S. (2011). *The SAGE handbook of qualitative research*. Sage.

Devillis, R. F., Devellis, B. M., Wallston, B. S., & Wallston, K. A. (1980). Epilepsy and learned helplessness. *Basic and Applied Social Psychology*, *1*(3), 241-253.

Devinsky, O. (1993). Clinical Uses of the Quality-of-Life in Epilepsy Inventory. *Epilepsia*, *34*(s4), S39-S44.

Devinsky, O., Vickrey, B. G., Cramer, J., Perrine, K., Hermann, B., Meador, K., & Hays, R. D. (1995). Development of the quality of life in epilepsy inventory. *Epilepsia*, *36*(11), 1089-1104.

Diener, E. (2000). Subjective well-being: The science of happiness and a proposal for a national index. *American Psychologist*, *55*(1), 34-43.

Diener, E., & Biswas-Diener, R. (2002). Will money increase subjective well-being?. *Social indicators research*, *57*(2), 119-169.

Diener, E., & Oishi, S. (2000). Money and happiness: Income and subjective well-being across nations. *Culture and subjective well-being*, 185-218.

Diener, E., Lucas, R. E., & Oishi, S. (2002). Subjective well-being. *Handbook of positive psychology*, 63-73.

Diener, E., Suh, E. M., Lucas, R. E., & Smith, H. L. (1999). Subjective well-being: Three decades of progress. *Psychological Bulletin*, *125*(2), 276-302.

DiIorio, C., Shafer, P. O., Letz, R., Henry, T. R., Schomer, D. L., Yeager, K., & Project EASE Study Group. (2006). Behavioral, social, and affective factors associated with self-efficacy for self-management among people with epilepsy.*Epilepsy & Behavior*, *9*(1), 158-163.

Doughty, J., Baker, G. A., Jacoby, A., & Lavaud, V. (2003). Cross cultural Differences in Levels of Knowledge about Epilepsy. *Epilepsia* 44 (1): 115-123.

Drinovac, M., Wagner, H., Agrawal, N., Cock, H. R., Mitchell, A. J., & von Oertzen, T. J. (2015). Screening for depression in epilepsy: A model of an enhanced screening tool. *Epilepsy & Behavior*, *44*, 67-72.

Dubois, B. (2010). Revising the definition of alzheimer's disease: A new lexicon. *Lancet Neurol*, *9*(11), 1118-1127.

Duncan, J. S., Sander, J. W., Sisodiya, S. M., & Walker, M. C. (2006). Adult epilepsy. *The Lancet*, *367*(9516), 1087-1100.

Eadie, M. J. (1995). Epilepsy—from the Sakikku to hughlings Jackson. *Journal of Clinical Neuroscience*, *2*(2), 156-162.

Egan, G. (2002). *The Skilled Helper: A Problem-Management and Opportunity-Development Approach to Helping*, Seventh Edition. Library of Congress-in-Publishing Data.

Elliott, J. O., & Richardson, V. E. (2014). The biopsychosocial model and quality of life in persons with active epilepsy. *Epilepsy & Behavior*, *41*, 55-65.

Ely, M., Vinz, R., Downing, M., & Anzul, M. (1997).*On Writing Qualitative Research: Living by words*. The falmer Press, Taylor & Francis Inc.

Endermann, M. (1997). Learned helplessness in epilepsy: A contribution toward the prediction of depression levels in a clinical setting. *Journal of Epilepsy, 10*(4), 161-171.

Engel, G. L. (1977). The need for a new medical model: a challenge for biomedicine. *Science*, *196*(4286), 129-136.

Engel, G. L. (1981). The clinical application of the biopsychosocial model. *Journal of Medicine and Philosophy*, *6*(2), 101-124.

Ezzy, D. (2001). Are qualitative methods misunderstood?. *Australian and New Zealand Journal of Public Health*, *25*(4), 294-297.

Fales, F. M. (2009). Mesopotamia. *Handbook of Clinical Neurology*, 95, 15-27 In Finger, S., Boller, K., Tyler, K. (2009). History of Neurology, (p.15-27), Amsterdam, Elsevier.

Fernandes, P. T., Noronha, A. L., Sander, J. W., & Li, L M. (2008). The perception of epilepsy stigma in different cities in Brazil. *Arq Neuropsiquitr* **66** (3-A), 471-476.

Fernandes, P. T., Salgado, P. C. B., Noronha, A. L. A., Bardosa, F. D., Souza, E. A. P., & Li, L. M. (2004). Stigma Scale of Epilepsy: Conceptual Issues. *Journal of Epilepsy and Clinical Neurophysiology* 10 (4): 213-218.

Fernandes, P. T., Salgado, P. C., Noronha, A. L. A., Barbosa, F. D., Souza, E. A., Sander, J. W., & Li, L. M. (2007a). Prejudice towards chronic diseases: comparison among epilepsy, AIDS and diabetes. *Seizure*, *16*(4), 320-323.

Fernandes, P. T., Salgado, P. C., Noronha, A. L., Sander, J. W., & Li, L. M. (2007b). Stigma scale of epilepsy: validation process. *Arquivos de neuro-psiquiatria*, *65,* 35-42.

Fernandes, P.T., Salgado, P. C. B., Noronha, A. L. A., de Boer, H. M., Prilipko, L., Sander, J. W. & Li, L.M. (2007c). Epilepsy stigma perception in an urban area of a limited-resource country. *Epilepsy & Behaviour,* Vol 11, p. 25-32.

Ferrans, C. E., Zerwic, J. J., Wilbur, J. E., & Larson, J. L. (2005). Conceptual model of health-related quality of life. *Journal of Nursing Scholarship, 37*(4), 336-342.

Festinger, L. (1954). A theory of social comparison processes. *Human relations*, *7*(2), 117-140.

Field, A. (2005). Discovering Statistics using SPSS, Second Edition. Sage Publishing Ltd.

Fiest, K. M., Dykeman, J., Patten, S. B., Wiebe, S., Kaplan, G. G., Maxwell, C. J., ... & Jette, N. (2013). Depression in epilepsy a systematic review and meta-analysis. *Neurology*, *80*(6), 590-599.

Fisher, R. S., Acevedo, C., Arzimanoglou, A., Bogacz, A., Cross, J. H., Elger, C. E., ... & Wiebe, S. (2014). ILAE official report: a practical clinical definition of epilepsy. *Epilepsia*, *55*(4), 475-482.

Fisher, R. S., Vickrey, B. G., Gibson, P., Hermann, B., Penovich, P., Scherer, A., & Walker, S. (2000). The impact of epilepsy from the patient's perspective I. Descriptions and subjective perceptions. *Epilepsy research*, *41*(1), 39-51.

Gallant, M. P. (2003). The influence of social support on chronic illness self-management: a review and directions for research. *Health Education & Behavior*, *30*(2), 170-195.

Gallefoss, F., Bakke, P. S., & RSGAARD, P. K. (1999). Quality of life assessment after patient education in a randomized controlled study on asthma and chronic obstructive pulmonary disease. *American Journal of Respiratory and Critical Care Medicine*, *159*(3), 812-817.

Gallop, K., Wild, D., Verdian, L., Kerr, M., Jacoby, A., Baker, G., ... & Cramer, J. A. (2010). Lennox-Gastaut syndrome (LGS): development of conceptual models of health-related quality of life (HRQL) for caregivers and children.*Seizure*, *19*(1), 23-30.

Ghanean, H., Jacobsson, L., & Nojomy, M. (2013). Self-perception of stigma in persons with epilepsy in Tehran, Iran. *Epilepsy & Behavior*, *28*(2), 163-167.

Ghanean, H., Nojomi, M., & Jacobsson, L. (2013). Public awareness and attitudes towards epilepsy in Tehran, Iran. *Global health action*, *6*.

Giray, S., Ozenli, Y., Ozisik, H., Karaca, S., & Aslaner, U. (2009). Health-related quality of life of patients with epilepsy in Turkey. *Journal of Clinical Neuroscience*, *16*(12), 1582-1587.

Goffman, E. (1963). Stigma: Notes on the Management of Spoiled Identity. Prentice-Hall Inc.

Goffman, E. (1969). *The presentation of self in everyday life*. London: Allen Lane.

Goldstein, L. H., Drew, C., Mellers, J., Mitchell-O'Malley, S., & Oakley, D. A. (2000). Dissociation, hypnotizability, coping styles and health locus of control: characteristics of pseudoseizure patients. *Seizure, 9*(5), 314-322.

Good, B. (1994). *Medicine, rationality and experience: an anthropological perspective* (No. 1990). Cambridge University Press.

Good, B. J. (1977). The heart of what's the matter: The semantics of illness in Iran. *Culture, medicine and psychiatry*, *1*(1), 25-58.

Gourie-Devi, M., Singh, V., Bala, K. (2010). Knowledge, attitudes and practices among patients of epilepsy attending tertiary hospital in Delhi, India and a review of Indian studies. *Neurology Asia*, 15 (3), 225-232.

Gouveia, V. V., & Ros, M. (2000). Hofstede and Schwartz's models for classifying individualism at the cultural level: their relation to macro-social and macro-economic variables1. *Psicothema*, *12*(Suplemento), 25-33.

Greener, M. (2014). Food for thought: The ketogenic diet for epilepsy. *Progress in Neurology and Psychiatry*, *18*(3), 6-9.

Guekht, A. B., Mitrokhina, T. V., Lebedeva, A. V., Dzugaeva, F. K., Milchakova, L. E., Lokshina, O. B., ... & Gusev, E. I. (2007). Factors influencing on quality of life in people with epilepsy. *Seizure*, *16*(2), 128-133.

Gunter, M. M. (2004). The Kurdish question in perspective. *World Affairs*, 197-205.

Hair, J. F., Black, W. C., Babin, B. J., Anderson, & Tatham, R. L. (2006). Multivariate Data Analysis Sixth Edition Pearson Education. *New Jersey*, 42-43.

Harden, C. L. (1997). Pseudoseizures and dissociative disorders: a common mechanism involving traumatic experiences. *Seizure*, *6*(2), 151-155.

Harden, C. L., Maroof, D. A., Nikolov, B., Fowler, K., Sperling, M., Liporace, J., Pennell, P, Labar, D., Herzog, A. (2007). The effect of seizure severity on quality of life in epilepsy. Epilepsy & Behavior 11 208–211.

Harkness, J. A., Van De Vijver, F. J. R., & Mohler, P. P.H. (2003). Cross-Cultural Survey Methods. John Wiley & Sons, Inc.

Hasan, S. S., Alen, Y. K. S., Wayne, W. G. W., Ahmadi, K., Anwar, M., & Goh, G. K. (2010). Understanding of and attitudes toward epilepsy among the urban Chinese population in Malaysia. *Singapore Medical Journal*, 51 (4), 290-299.

Hassan, Z. (2013). Kurdish nationalism: What are its origins?. *International Journal of Contemporary Iraqi Studies*, *7*(2), 75-89.

Hayes, S. (2004). Acceptance and Commitment Therapy, Relational Frame Theory, and the Third Wave of Behavioural and Cognitive Therapies. *Behaviour Therapy*, 35, 639-665.

Heaney, D. C., MacDonald, B. K., Everitt, A., Stevenson, S., Leonardi, G. S., Wilkinson, P., & Sander, J. W. (2002). Socioeconomic variation in incidence of epilepsy: prospective community based study in south east England. *Bmj*,*325*(7371), 1013-1016.

Hebl, M. R., & Kleck, R. E. (2000). The social consequences of physical disability. *The social psychology of stigma*, 419-439.

Hecimovic, H., Santos, J. M., Carter, J., Attarian, H. P., Fessler, A. J., Vahle, V., & Gilliam, F. (2012). Depression but not seizure factors or quality of life predicts suicidality in epilepsy. *Epilepsy & Behavior*, *24*(4), 426-429.

Hermann, B. P., Vickrey, B., Hays, R. D., Cramer, J., Devinsky, O., Meador, K., ... & Ellison, G. W. (1996). A comparison of health-related quality of life in patients with epilepsy, diabetes and multiple sclerosis. *Epilepsy Research*,*25*(2), 113-118.

Hills, M. D., & Baker, P. G. (1992). Relationships among epilepsy, social stigma, self-esteem, and social support. *Journal of epilepsy*, *5*(4), 231-238.

Hofstede, G. (1980). Culture and organizations. *International Studies of Management & Organization*, *10*(4), 15-41.

Hofstede, G. (1984). *Culture's consequences: International differences in work-related values* (Vol. 5). sage.

Hofstede, G., Hofstede, G. J., & Minkov, M. (1991). *Cultures and organizations: Software of the mind* (Vol. 2). London: McGraw-Hill.

Hollway,W. & Jefferson, T. (2002). *Doing Qualitative Research differently: Free Association, Narrative and the interview method*. Sage.

Hopkins, A., & Appleton, R. (1996). Epilepsy, the facts. Oxford University Press.

Hoppe, C., & Elger, C. E. (2011). Depression in epilepsy: a critical review from a clinical perspective. *Nature Reviews Neurology*, *7*(8), 462-472.

Hosseini, N., Sharif, F., Ahmadi, F., & Zare, M. (2010). Striving for balance: coping with epilepsy in Iranian patients. *Epilepsy & Behavior*, *18*(4), 466-471.

Hout, B., Gagnon, D., Souetre, E., Ried, S., Remy, C., Baker, G., ... & McNulty, P. (1997). Relationship between seizure frequency and costs and quality of life of outpatients with partial epilepsy in France, Germany, and the United Kingdom. *Epilepsia*, *38*(11), 1221-1226.

Hovinga, C. A., Asato, M. R., Manjunath, R., Wheless, J. W., Phelps, S. J., Sheth, R. D., ... & Haskins, L. S. (2008). Association of non-adherence to antiepileptic drugs and seizures, quality of life, and productivity: survey of patients with epilepsy and physicians. *Epilepsy & Behavior*, *13*(2), 316-322.

Hsieh, H. F., & Shannon, S. E. (2005). Three approaches to qualitative content analysis. *Qualitative health research*, *15*(9), 1277-1288.

Huppert, F. A., & Whittington, J. E. (2003). Evidence for the independence of positive and negative well-being: Implications for quality of life assessment. *British journal of health psychology*, *8*(1), 107-122.

Husain, A. M., & Sinha, S. R. (2011). Nocturnal epilepsy in adults. *Journal of Clinical Neurophysiology*, *28*(2), 141-145.

Hyland, M. E., Finnis, S., & Irvine, S. H. (1991). A scale for assessing quality of life in adult asthma sufferers. *Journal of psychosomatic research*, *35*(1), 99-110.

ILAE Website, (2014): http://www.ilae.org/Visitors/Centre/Index.cfm

IJzerman, H., & Cohen, D. (2011). Grounding cultural syndromes: Body comportment and values in honor and dignity cultures. *European Journal of Social Psychology*, *41*(4), 456-467.

International League against Epilepsy. (2014). Fisher, R. S., Acevedo, C., Arzimanoglou, A., Bogacz, A., Cross, H., Elger, C. E., Engel Jr, J., Forsgren, L., French, J. A., Glynn, M., Hesdorffer, C., Lee, B. I., Mathern, G. W., Mosh_e, S. L., Perucca, E., Scheffer, I. E., Tomson. T.,Watanabe, M., & Wiebe, S. A practical clinical definition of epilepsy. Epilepsia, 55(4):475–482.

Ismail, H., Wright, J., Rhodes, P., & Small, N. (2005). Religious beliefs about causes and treatment of epilepsy. *British Journal of General Practice*, *55*(510), 26-31.

Jacoby, A. (1992). Epilepsy and the quality of everyday life: findings from a study of people with well-controlled epilepsy. *Social science & medicine*, *34*(6), 657-666.

Jacoby, A. (2002). Stigma, epilepsy, and quality of life. *Epilepsy & Behavior*,*3*(6), 10-20.

Jacoby, A., & Baker, G. A. (2008). Quality-of-life trajectories in epilepsy: a review of the literature. *Epilepsy & Behavior*, *12*(4), 557-571.

Jacoby, A., & Austin, J. K. (2007) Social stigma for adults and children with epilepsy. *Epilepsia*, 48(9), 6-9.

Jacoby, A., de Boer, H., Prilipko, L., Baker, G., Wang, W., Vu, T. D., . . . Begley, C. (2008). Meanings of epilepsy in its sociocultural context and implications for stigma: Findings from ethnographic studies in local communities in china and vietnam. *Epilepsy and Behavior, 12*(2), 286-297.

Jacoby, A., Gorry, J., Gamble, C., & Baker, G. A. (2004). Public knowledge, private grief: a study of public attitudes to epilepsy in the United Kingdom and implications for stigma. *Epilepsia*, *45*(11), 1405-1415.

Jacoby, A., Snape, D., & Baker, G. A. (2005). Epilepsy and social identity: the stigma of a chronic neurological disorder. *The Lancet Neurology*, *4*(3), 171-178.

Jacoby, A., Snape, D., Lane, S., & Baker, G. A. (2015). Self-reported anxiety and sleep problems in people with epilepsy and their association with quality of life. *Epilepsy & Behavior*, *43*, 149-158.

Jagosh, J., & Boudreau, D. (2009). Lost and found in translation: an ecological approach to bilingual research methodology. *International Journal of Qualitative Methods*, *8*(2), 102-114.

Jerant, A. F., Friederichs-Fitzwater, M. M von., & Moore, M. (2005) Patients' perceived barriers to active self-management of chronic conditions. *Patient Education and Counselling* 57 300–307.

Joachim, G., & Acorn, S. (2000). Stigma of visible and invisible chronic conditions. *Journal of advanced nursing*, *32*(1), 243-248.

Johnson, E. K., Jones, J. E., Seidenberg, M., & Hermann, B. P. (2004). The Relative Impact of Anxiety, Depression, and Clinical Seizure Features on Health-related Quality of Life in Epilepsy. *Epilepsia*, *45*(5), 544-550.

Jones, E. E., Farina, A., Hastorf, A. H., Markus, H., Miller, D. T., & Scott, R. A. (1984). *Social Stigma: The Psychology of Marked Relationships*. W. H. Freeman and Company.

Jones, R. M., Butler, J. A., Thomas, V. A., Peveler, R. C., & Prevett, M. (2006). Adherence to treatment in patients with epilepsy: associations with seizure control and illness beliefs. *Seizure*, *15*(7), 504-508.

Jones, R. M., Butler, J. A., Thomas, V. A., Peveler, R. C., & Prevett, M. (2006). Adherence to treatment in patients with epilepsy: associations with seizure control and illness beliefs. *Seizure, 15*(7), 504-508.

Julian, J. W., & Katz, S. B. (1968). Internal versus external control and the value of reinforcement. *Journal of Personality and Social Psychology*, *8*(1), 89-94.

Kahneman, D. (1999). 1 Objective Happiness. *Well-being: Foundations of hedonic psychology*, 1.

Kahneman, D. (2003). 1 Objective Happiness. *Well-being: Foundations of hedonic psychology*, 1.

Kahneman, D., Krueger, A. B., Schkade, D., Schwarz, N., & Stone, A. A. (2006). Would you be happier if you were richer? A focusing illusion. *science,312*(5782), 1908-1910.

Kale, R. (1997). Bringing epilepsy out of the shadows. *BMJ: British Medical Journal*, *315*(7099), 2.

Kaleyias, J., Tzoufi, M., Kotsalis, C., Papavasiliou, A., & Diamantopoulos, N. (2005). Knowledge and attitude of the Greek educational community toward epilepsy and the epileptic student. *Epilepsy & Behaviour*, 6, 127-186.

Kannathal, N., Choo, M. L., Acharya, U. R., & Sadasivan, P. K. (2005). Entropies for detection of epilepsy in EEG. Computer methods and programs in biomedicine, 80(3), 187-194.

Kanner, A. M. (2006). Depression and epilepsy: a new perspective on two closely related disorders. *Epilepsy Currents*, *6*(5), 141-146.

Kashima, Y., Yamaguchi, S., Kim, U., Choi, S. C., Gelfand, M. J., & Yuki, M. (1995). Culture, gender, and self: a perspective from individualism-collectivism research. *Journal of personality and social psychology*, *69*(5), 925.

Kaski, D., & Cockerell, C. (2015). Advances in the diagnosis and management of epilepsy in adults. *Prescriber*, *26*(3), 12-19.

Katz, I. (1981). Stigma: A Social Psychological Analysis. Lawrence Erlbaum Associates, Inc., Publishers.

Kelso, A. R., & Cock, H. R. (2004). Advances in epilepsy. *British medical bulletin*, *72*(1), 135-148.

Kemp, S., Morley, S., & Anderson, E. (1999). Coping with epilepsy: Do illness representations play a role?. *British Journal of Clinical Psychology*, *38*(1), 43-58.

Kendrick, A. M., & Trimble, M. R. (1992). Patient-perceived quality of life: what is important to the patient with epilepsy?. *Seizure*, *1*(suppl A), 1-10.

Kessler, E. H. (Ed). (2013). *Encyclopedia of management theory*. (Vols. 1-2). Thousand Oaks, CA: SAGE Publications, Inc.

Khidr, A. H., & Sheikh-Bzeni, A. S. (2011). Prevalence of epilepsy in Hawler City; a household survey. *Zanco Journal Medical Science*, *15*(3), 12-18.

Kim, D. Y., & Rho, J. M. (2008). Current Opinion in Clinical Nutrition and Metabolic Care, 11(2), 113-120.

King, M., Dinos, S., Shaw, J., Watson, R., Stevens, S., Passetti, F., ... & Serfaty, M. (2007). The Stigma Scale: development of a standardised measure of the stigma of mental illness. *The British Journal of Psychiatry*, *190*(3), 248-254.

Kleck, R. (1968). Physical stigma and nonverbal cues emitted in face-to-face interaction. *Human Relations*.

Kleck, R. E. (1968). Self-disclosure Patterns of the Nonobviously Stigmatized.*Psychological reports*, *23*(3f), 1239-1248.

Kleck, R., Buck, P. L., Goller, W. L.,London, R. S., Pfeiffer, J. R., & Vukcevic, D. P. (1968). Effect of Stigmatizing Conditions on the Use of Personal Space. *Psychological Reports*, 23 (11), 111-118.

Kobau, R., & DiIorio, C. (2003). Epilepsy self-management: a comparison of self-efficacy and outcome expectancy for medication adherence and lifestyle behaviors among people with epilepsy. *Epilepsy & Behavior*, *4*(3), 217-225.

Kondziella, D., & Asztely, F. (2009). Don't be afraid to treat depression in patients with epilepsy!. *Acta Neurologica Scandinavica*, *119*(2), 75-80.

Krakow, K., Bühler, K. E., & Haltenhof, H. (1999). Coping with refractory epilepsy. *Seizure*, *8*(2), 111-115.

Kumari, P., Ram, D., Nizamie, S. H., & Goyal, N. (2009). Stigma and quality of life in individuals with epilepsy: a preliminary report. *Epilepsy & Behavior*, *15*(3), 358-361.

Kuyken, W., & Orley, J. (1994). Development of the WHOQOL-Rationale and Current Status. *International Journal of Mental Health*, *23*(3), 24-56.

Kwan, P., & Sander, J. W. (2004). The natural history of epilepsy: an epidemiological view. *Journal of Neurology, Neurosurgery & Psychiatry*, *75*(10), 1376-1381.

Labar, D. (2004). Vagus nerve stimulation for epilepsy. *Clinical Neuroscience Research*, *4*(1), 81-87.

Laubmeier, K. K., Zakowski, S. G., & Bair, J. P. (2004). The role of spirituality in the psychological adjustment to cancer: A test of the transactional model of stress and coping. *International journal of behavioral medicine*, *11*(1), 48-55.

Le, S., Shafer, P. O., Bartfeld, E., & Fisher, R. S. (2011). An online diary for tracking epilepsy. *Epilepsy & Behavior*, *22*(4), 705-709.

Lee, S. A., Yoo, H. J., Lee, B. I., & Korean QoL in Epilepsy Study Group. (2005). Factors contributing to the stigma of epilepsy. *Seizure*, *14*(3), 157-163.

Leidy, N. K., Elixhauser, A., Vickrey, B., Means, E., & Willian, M. K. (1999). Seizure frequency and the health-related quality of life of adults with epilepsy.*Neurology*, *53*(1), 162-162.

Lewinsohn, P. M. (1974). As cited in Griffiths, D. (1981). *Psychology and medicine*. London: Macmillan.

Leyshon, S. (2005). Neurological conditions. *Primary Health Care, 15*(10), 8.

Link, B. G., & Phelan, J. C. (2001). Conceptualizing stigma. *Annual review of Sociology*, 363-385.

Link, B. G., & Phelan, J. C. (2006). Stigma and its public health implications. *The Lancet*, *367*(9509), 528-529.

Linley, P. A., Maltby, J., Wood, A. M., Osborne, G., & Hurling, R. (2009). Measuring happiness: The higher order factor structure of subjective and psychological well-being measures. *Personality and Individual Differences, 47*(8), 878-884.

Liveh, H., Wilson, L. M., Duchesneau, A., & Antonak, R. F. (2001). Psychosocial Adaptation to Epilepsy: The Role of Coping Strategies. *Epilepsy & Behaviour*, **2**, 533-544.

Long, L., Reeves, A. L., Moore, J. L., Roach, J., & Pickering, C. T. (2000). An assessment of epilepsy patients' knowledge of their disorder. *Epilepsia*, *41*(6), 727-731.

Loring, D. W., Meador, K. J., & Lee, G. P. (2004). Determinants of quality of life in epilepsy. *Epilepsy & Behavior, 5*(6), 976-980.

Lowenstein, D. H., Bleck, T., & Macdonald, R. L. (1999). It's time to revise the definition of status epilepticus. *Epilepsia*, *40*(1), 120-122.

Lundgren, T., Dahl, J., Yardi, N., & Melin, L. (2008). Acceptance and commitment therapy and yoga for drug-refractory epilepsy: a randomized controlled trial. *Epilepsy & Behavior, 13*(1), 102-108.

Magiorkinis, E., Sidiropoulou, K., & Diamantis, A. (2010). Hallmarks in the history of epilepsy: epilepsy in antiquity. *Epilepsy & behavior*, *17*(1), 103-108.

Maroufi, A., Khomand, P., Ahmadiani, S., Alizadeh, N. S., & Gharibi, F. (2014). Prevalence and quality of anxiety in patients with epilepsy. *Epilepsy & Behavior*, *32*, 34-37.

Matsumoto, D. (2000). Culture and psychology: People around the world . USA: Wadsworth.

Masia, S. L., & Devinsky, O. (2000). Epilepsy and behavior: A brief history.*Epilepsy & Behavior*, *1*(1), 27-36.

Masoudnia, E. (2009). Awareness, understanding and attitudes towards epilepsy among Iranian ethnic groups. *Seizure*, *18*(5), 369-373.

Matos, G., Andersen, M. L., Valle, A. C. D., Tufik, S. (2010). The relationship between sleep and epilepsy: Evidence from clinical trials and animal models. *Journal of the Neurological Sciences* 295, 1–7.

Maxwell, S. E. (2000). Sample size and multiple regression analysis. *Psychological methods*, *5*(4), 434.

Mbuba, C. K., & Newton, C. R. (2009). Packages of care for epilepsy in low-and middle-income countries. *PLoS medicine*, *6*(10), 1106.

McCagh, J. (2014). Quality of Life Issues in Epilepsy.

McEwan, L., Taylor, J., Casswell, M., Entwistle, R., Jacoby, K., Jacoby, A., . . . Baker, G. A. (2007). Knowledge of and attitudes expressed toward epilepsy by carers of people with epilepsy: A UK perspective. *Epilepsy and Behavior, 11*(1), 13-19.

McLaughlin, D. P., Pachana, N. A., & Mcfarland, K. (2008). Stigma, seizure frequency and quality of life: the impact of epilepsy in late adulthood. *Seizure*,*17*(3), 281-287.

Mead, G. H., & Mind, H. (1934). Self and society. *Chicago: University of Chicago*, 173-175.

Mecarelli, O., Voti, P. L., Vanacore, N., D’Arcangelo, S., Mingoia, M., Pulitano, P., & Accornero, N. (2007). A questionnaire study on knowledge of and attitudes toward epilepsy in schoolchildren and university students in Rome, Italy. *Seizure*, 16, 313-319.

Mehndiratta, P., & Sajatovic, M. (2013). Treatments for patients with comorbid epilepsy and depression: a systematic literature review. *Epilepsy & Behavior*, *28*(1), 36-40.

Meho, L. I., & Maglaughlin, K. L. (2001). *Kurdish culture and society: an annotated bibliography* (No. 9). Greenwood Publishing Group.

Micoulaud-Franchi, J. A., Barkate, G., Trébuchon-Da Fonseca, A., Vaugier, L., Gavaret, M., Bartolomei, F., & McGonigal, A. (2015). One step closer to a global tool for rapid screening of major depression in epilepsy: Validation of the French NDDI-E. *Epilepsy & Behavior*, *44*, 11-16.

Mikulincer, M. (2013). *Human learned helplessness: A coping perspective*. Springer Science & Business Media.

Mirnics, Z., Bekes, J., Rozsa, S., & Halasz, P. (2001). Adjusting and Coping in Epilepsy. *Seizure*, 10, 181-187.

Mofidi, N., Ghazinour, M., Araste, M., Jacobsson, L., & Richter, J. (2008). General mental health, quality of life and suicide-related attitudes among kurdish people in iran. *International Journal of Social Psychiatry*, *54*(5), 457-468.

Moran, N. F., Poole, K., Bell, G., Solomon, J., Kendall, S., McCarthy, M., ... & Shorvon, S. D. (2004). Epilepsy in the United Kingdom: seizure frequency and severity, anti-epileptic drug utilization and impact on life in 1652 people with epilepsy. *Seizure*, *13*(6), 425-433.

Morgan, C. L. I., Ahmed, Z., & Kerr, M. P. (2000). Social deprivation and prevalence of epilepsy and associated health usage. *J Neurol Neurosurg Psychiatry* 2000;69:13–17.

Morrell, M. J. (2002). Stigma and epilepsy. *Epilepsy & Behavior*, *3*(6), 21-25.

Mrabet, H., Mrabet, A., Zouari, B., & Ghachem, R. (2004). Health-related Quality of Life of People with Epilepsy Compared with a General Reference Population: A Tunisian Study. *Epilepsia*, *45*(7), 838-843.

Ndoye, N. F., Sow, A. D., Diop, A. G., Sessouma, B., Sene-Diouf, F., Boissy, L., ... & Sander, J. W. A. S. (2005). Prevalence of epilepsy its treatment gap and knowledge, attitude and practice of its population in sub-urban Senegal an ILAE/IBE/WHO study. *Seizure*, *14*(2), 106-111.

Newman, I. & Benz, R. C. (1998). *Qualitative-Quantitative Research Methodology: Exploring the Interactive Continuum.* Southern Illinois University press. Carbondale, IL.

Newton, C. R., & Garcia, H. H. (2012). Epilepsy in poor regions of the world.*The Lancet*, *380*(9848), 1193-1201.

Ngugi, A. K., Kariuki, S. M., Bottomley, C., Kleinschmidt, I., Sander, J. W., & Newton, C. R. (2011). Incidence of epilepsy A systematic review and meta-analysis. *Neurology*, *77*(10), 1005-1012.

NICE (National Institute for Health & Care Excellence). (2015). http://cks.nice.org.uk/epilepsy#!topicsummary

Nightingale, D. J., & Cromby, J. (1999). *Social constructionist psychology: a critical analysis of theory and practice*. Open University Press.

Oishi, S., Diener, E., Suh, E., & Lucas, R. E. (1999). Value as a moderator in subjective well-being. *Journal of personality*, *67*(1), 157-184.

O'Leary, C. A. (2002). The Kurds of Iraq: recent history, future prospects.*Middle East Review of International Affairs*, *6*(4), 17-29.

Ohaeri, J. U., Awadalla, A. W., & Farah, A. A. (2009). Quality of life in people with epilepsy and their family caregivers. An Arab experience using the short version of the World Health Organization quality of life instrument. *Saudi medical journal*, *30*(10), 1328-1335.

Okun, M. S., Bowers, D., Springer, U., Shapira, N. A., Malone, D., Rezai, A. R., & Goodman, W. K. (2004). What's in a "smile?" Intra-operative observations of contralateral smiles induced by deep brain stimulation. *Neurocase*, *10*(4), 271-279.

Otoom, S. A., Al-Safi, S. A., Sequeira, R. P., & Alkofahi, A. S. (2006). Knowledge of management of epilepsy in young adults in Jordan. *Epilepsy & Behavior*, *9*(2), 349-354.

Oyserman, D., Coon, H. M., & Kemmelmeier, M. (2002). Rethinking individualism and collectivism: evaluation of theoretical assumptions and meta-analyses. *Psychological bulletin*, *128*(1), 3.

Pais-Ribeiro, J., da Silva, A. M., Meneses, R. F., & Falco, C. (2007). Relationship between optimism, disease variables, and health perception and quality of life in individuals with epilepsy. *Epilepsy & Behavior*, *11*(1), 33-38.

Pavlou, E., Gkampeta, A., & Athanasiadou- Piperopoulou, F. (2012). Benign epilepsy with centro-temporal spikes (BECTS): relationship between unilateral or bilateral localization of interictal stereotyped focal spikes on EEG and the effectiveness of anti-epileptic medication. HIPPOKRATIA, 16 (3), 221-224.

Phillips, D. (2006). *Quality of life: Concept, policy and practice*. London: Routledge.

Pickrell, W. O., Lacey, A. S., Bodger, O. G., Demmler, J. C., Thomas, R. H., Lyons, R. A., ... & Kerr, M. P. (2015). Epilepsy and deprivation, a data linkage study. *Epilepsia*, *56*(4), 585-591.

Rafael, F., Dubreuil, C-M., Burbaud, F., Tran, D. S., Clement, J-P., Preux, P-M., Nubukpo, P. (2010). Knowledge of epilepsy in the general population based on two French cities: Implications for stigma. *Epilepsy & Bhavior*, 17, 82-86.

Raggi, A., Leonardi, M., D'Amico, D., Villani, F., & Quintas, R. (2015). A Step Forward on Similarities Between Migraine and Epilepsy: Psychosocial Difficulties. *Headache: The Journal of Head and Face Pain*.

Rahim, T. A., Saeed, B. A., Farhan, H. M., & Aziz, R. R. (2015). Trends of Indigenous Healing Among People with Psychiatric Disorders: Comparative Study of Arabic and Kurdish Ethnicities in Iraq. *Journal of religion and health,54*(1), 316-326.

Ramaratnam, S. (2001). Yoga for epilepsy: methodological issues. *Seizure*, 10: 3–6.

Ramaratnam, S., Baker, G. A., & Goldstein, L. H. (2008). Psychological treatments for epilepsy. *Cochrane Database of Systematic Reviews,* Issue 3.

Regmi, K., Naidoo, J., & Pilkington, P. (2010). Understanding the processes of translation and transliteration in qualitative research. *International Journal of Qualitative Methods*, *9*(1), 16-26.

Riessman, C. K. (1993). *Narrative Analysis: Qualitative Research Methods Series 30*. Sage.

Ritchie, J., Lewis, J., Nicholls, C. M., & Ormston, R. (Eds.). (2013). *Qualitative research practice: A guide for social science students and researchers*. Sage.

Rogers, C. R. (1994). *Client-Centred Therapy*. Published by Constables and Company Limited.

Rosenbaum, M. (1984). Helplessness and resourcefulness in coping with epilepsy. *Journal of Consulting and Clinical Psychology*, Vol 52(2), 244-253.

Rosenbaum, P., Paneth, N., Leviton, A., Goldstein, M., Bax, M., Damiano, D., ... & Jacobsson, B. (2007). A report: the definition and classification of cerebral palsy April 2006. *Dev Med Child Neurol Suppl*, *109*(suppl 109), 8-14.

Rossor, M. N., Iversen, L. L., Reynolds, G. P., Mountjoy, C. Q., & Roth, M. (1984). Neurochemical characteristics of early and late onset types of Alzheimer's disease. *BMJ*, *288*(6422), 961-964.

Ryff, C. D. (1989). Happiness is everything, or is it? Explorations on the meaning of psychological well-being. *Journal of personality and social psychology*, *57*(6), 1069.

Sancho, J., Iváñez, V., Molins, A., Gómez, V. L., Masramón, X., & Pérez, M. (2010). Changes in seizure severity and quality of life in patients with refractory partial epilepsy. *Epilepsy & Behavior*, *19*(3), 409-413.

Santos, I. C., Guerreiro, M. M., Mata, A., GUIMARÃES, R., Fernandes, L., Moreira Filho, D. C., & Guerreiro, C. A. (1998). Public awareness and attitudes toward epilepsy in different social segments in Brazil. *Arquivos de neuro-psiquiatria*, *56*(1), 32-38.

Santosh, D., Kumar, T. S., Sarma, P. S., & Radhakrishnan, K. (2007). Women with onset of epilepsy prior to marriage: disclose or conceal?. *Epilepsia*, *48*(5), 1007-1010.

Sawangchareon, K., Pranboon, S., Tiamkao, S., & Sawanyawisuth, K. (2013). Moving the self-esteem of people with epilepsy by supportive group: a clinical trial. *Journal of Caring Sciences, 2*(4), 329-335.

Saxena, S., & Orley, J. (1997). Quality of life assessment: the World Health Organization perspective. *European psychiatry*, *12*, 263s-266s.

Scambler, G. (1993). Epilepsy and quality of life research. *Journal of the Royal Society of Medicine*, *86*(8), 449.

Scambler, G. (1998). Stigma and disease: changing paradigms. *The Lancet*,*352*(9133), 1054-1055.

Scambler, G., & Hopkins, A. (1990). Generating a model of epileptic stigma: The role of qualitative analysis. *Social Science & Medicine, 30*(11), 1187-1194.

Schalock, R. L., & Felce, D. (2004). Quality of life and subjective well-being: Conceptual and measurement issues. *International handbook of applied research in intellectual disabilities*, 261-279.

Schlenk, E. A., Erlen, J. A., Dunbar-Jacob, J., McDowell, J., Engberg, S., Sereika, S. M., ... & Bernier, M. J. (1997). Health-related quality of life in chronic disorders: a comparison across studies using the MOS SF-36. *Quality of Life Research*, *7*(1), 57-65.

Schmidt, D. (2009). Drug treatment of epilepsy: Options and limitations. *Epilepsy & Behavior* 15, 56–65.

Schwartz, S. H. (1990). Individualism-collectivism critique and proposed refinements. *Journal of cross-cultural psychology*, *21*(2), 139-157.

Scott, R. A., Lhatoo, S. D., & Sander, J. W. (2001). The treatment of epilepsy in developing countries: where do we go from here?. *Bulletin of the World Health Organization*, *79*(4), 344-351.

Scott-Lennox, J., Bryant-Comstock, L., Lennox, R., & Baker, G. A. (2001). Reliability, validity and responsiveness of a revised scoring system for the Liverpool Seizure Severity Scale. *Epilepsy research*, *44*(1), 53-63.

Shakir, M., & Al-Asadi, J. N. (2012). Quality of life and its determinants in people with epilepsy in Basrah, Iraq. *Sultan Qaboos University medical journal*, *12*(4), 449.

Shehata, G. A., & Mahran. D. G. (2011). Knowledge and attitude of epilepsy among secondary schools students (epileptic and non-epileptic) in Assiut city ‘‘Egypt’’. *Epilepsy Research*, 95, 130-135.

Sillanpää, M., & Schmidt, D. (2006). Natural history of treated childhood-onset epilepsy: prospective, long-term population-based study. *Brain*, *129*(3), 617-624.

Siraj, A. (2011). Meanings of modesty and the hijab amongst Muslim women in Glasgow, Scotland. *Gender, Place & Culture*, *18*(6), 716-731.

Smith, J. A. (Ed.). (2015). *Qualitative psychology: A practical guide to research methods*. Sage.

Smith, J. A., Harre, R., & Langenhove, L. V. (1995). Rethinking Methods in Psychology, Sage.

Smith, S. J. M. (2005). EEG in the diagnosis, classification, and management of patients with epilepsy. *Journal of Neurology, Neurosurgery & Psychiatry*,*76*(suppl 2), ii2-ii7.

Snape, D., Wang, W., Wu, J., Jacoby, A., & Baker, G. A. (2009). Knowledge gaps and uncertainties about epilepsy: findings from an ethnographic study in China. *Epilepsy & Behavior*, *14*(1), 172-178.

Søndergaard, H. P., Ekblad, S., & Theorell, T. (2001). Self-reported life event patterns and their relation to health among recently resettled Iraqi and Kurdish refugees in Sweden. *The Journal of nervous and mental disease*, *189*(12), 838-845.

Sperling, M. R., Schilling, C. A., Glosser, D., Tracy, J. I., & Asadi-Pooya, A. A. (2008). Self-perception of seizure precipitants and their relation to anxiety level, depression, and health locus of control in epilepsy. *Seizure*, *17*(4), 302-307.

Sprangers, M. A., & Schwartz, C. E. (1999). Integrating response shift into health-related quality of life research: a theoretical model. *Social science & medicine*, *48*(11), 1507-1515.

Sridharan, R. (2002). Epidemiology of epilepsy. *Curr Sci*, *82*(6), 664-670.

Srinivasa Murthy, R. (2007). Mass violence and mental health--Recent epidemiological findings. *International Review of Psychiatry*, *19*(3), 183-192.

Stanton, A. L., Revenson, T. A., & Tennen, H. (2007). Health psychology: psychological adjustment to chronic disease. *Annu. Rev. Psychol.*, *58*, 565-592.

Stone, J., Binzer, M., & Sharpe, M. (2004). Illness beliefs and locus of control: a comparison of patients with pseudoseizures and epilepsy. *Journal of psychosomatic research*, *57*(6), 541-547.

Stryker, S., & Statham, A. (1985). Symbplic Interaction and Role Theory. In Lindzey, G. (3rd Ed.). *Handbook of social psychology* (Vol. 1) (pp. 311-378). New York: Random house.

Sturges, J. E., & Hanrahan, K. J. (2004). Comparing telephone and face-to-face qualitative interviewing: a research note. *Qualitative Research*, *4*(1), 107-118.

Suurmeijer, T. P., Reuvekamp, M. F., & Aldenkamp, B. P. (2001). Social functioning, psychological functioning, and quality of life in epilepsy. *Epilepsia*,*42*(9), 1160-1168.

Sawangchareon, K., Pranboon, S., Tiamkao, S., & Sawanyawisuth, K. (2013). Moving the Self-Esteem of People with Epilepsy by Supportive Group: A Clinical Trial. Journal of Caring Sciences, 2, 329-335.

Tabachnik, B. G., & Fidell, L. S. (2007). Using Multivariate Statistics, Fifth Edition. Pearson Education, Inc.

Taloyan, M., Johansson, L. M., Saleh-Stattin, N., & Al-Windi, A. (2011). Acculturation strategies in migration stress among Kurdish men in Sweden: a narrative approach. *American journal of men's health*, *5*(3), 198-207.

Tamber, M. S., & Mountz, J. M. (2012, November). Advances in the diagnosis and treatment of epilepsy. In *Seminars in nuclear medicine* (Vol. 42, No. 6, pp. 371-386). WB Saunders.

Tawfik-Shukor, A., & Khoshnaw, H. (2010). The impact of health system governance and policy processes on health services in iraqi kurdistan. *BMC International Health and Human Rights*, *10*(1), 14-14.

Taylor, R. S., Sander, J. W., Taylor, R. J., & Baker, G. A. (2011). Predictors of health-related quality of life and costs in adults with epilepsy: A systematic review. *Epilepsia*, *52*(12), 2168-2180.

Taylor, S. E. (1983). Adjustment to threatening events: A theory of cognitive adaptation. *American psychologist*, *38*(11), 1161.

Tedrus, G. M. D. A. S., Fonseca, L. C., & Carvalho, R. M. (2013). Epilepsy and quality of life: socio-demographic and clinical aspects, and psychiatric co-morbidity. *Arquivos de neuro-psiquiatria*, *71*(6), 385-391.

Tekle-Haimanot, R., Abebe, M., Forsgren, L., Gebre-Mariam, A., Heubel, J., Holmgren, G., Ekstedt, J. (1991). Attitudes of Rural People in Central Ethiopia Towards Epilepsy. *Social Science & Medicine*, Vol 32 (2), 203-209.

Temkin, O. (1994). *The falling sickness: a history of epilepsy from the Greeks to the beginnings of modern neurology*. JHU Press.

Tolin, D. F., & Foa, E. B. (2006). Sex differences in trauma and posttraumatic stress disorder: a quantitative review of 25 years of research. *Psychological bulletin*, *132*(6), 959.

Triandis, H. C., Brislin, R., Hui, C. H (1988).Cross-Cultural Training Across the Individualism-Collectivism Divide. *International Journal of Intercultural Relations*, 12, 265-289.

Tröster, H. (1997). Disclose or conceal? Strategies of information management in persons with epilepsy. *Epilepsia*, *38*(11), 1227-1237.

Uskul, A. K., Cross, S. E., Günsoy, C., Gerçek-Swing, B., Alözkan, C., & Ataca, B. (2015). A price to pay: Turkish and Northern American retaliation for threats to personal and family honor. *Aggressive behavior*, *41*(6), 594-607.

Üstün, T. B., Chatterji, S., Bickenbach, J., Kostanjsek, N., & Schneider, M. (2003). The International Classification of Functioning, Disability and Health: a new tool for understanding disability and health. *Disability and rehabilitation*,*25*(11-12), 565-571.

van Bruinessen, M. M. (2007). The Kurds in movement: Migrations, mobilisations, communications and the globalisation of the Kurdish question.

Veenhoven, R. (1999). Quality-of-life in individualistic society. *Social Indicators Research*, *48*(2), 159-188.

Velissaris, S. L., Wilson, S. J., Saling, M. M., Newton, M. R., & Berkovic, S. F. (2007). The psychological impact of a newly diagnosed seizure: losing and restoring perceived control. *Epilepsy & Behavior*, *10*(2), 223-233.

Vîlceanu, A. (2008). Being a Translator/Interpreter. *THE MINISTRY OF EDUCATION, RESEARCH AND YOUTH*, 40.

Vonck, K., Raedt, R., & Boon, P. (2010). Vagus nerve stimulation and the postictal state. *Epilepsy and Behavior*,*19*(2), 182-185.

Walker, J. G., Jackson, H. J., & Littlejohn, G. O. (2004). Models of adjustment to chronic illness: using the example of rheumatoid arthritis. *Clinical psychology review*, *24*(4), 461-488.

Wang, W. Z., Wu, J. Z., Wang, D. S., Dai, X. Y., Yang, B., Wang, T. P., ... & Sander, J. W. (2003). The prevalence and treatment gap in epilepsy in China An ILAE/IBE/WHO study. *Neurology*, *60*(9), 1544-1545.

Weiss, M. (1997). The explanatory model interview catalogue (EMIC) for cultural study of illness experience. *European Psychiatry*, *12*, 136s.

Weiss, M. G., Doongaji, D. R., Siddhartha, S., Wypij, D., Pathare, S., Bhatawdekar, M., ... & Fernandes, R. (1992). The Explanatory Model Interview Catalogue (EMIC). Contribution to cross-cultural research methods from a study of leprosy and mental health. *The British Journal of Psychiatry*,*160*(6), 819-830.

Weiss, M. G., & Ramakrishna, J. (2006). Stigma interventions and research for international health. *The Lancet*, *367*(9509), 536-538.

Whatley, A. D., DiIorio, C. K., & Yeager, K. (2010). Examining the relationships of depressive symptoms, stigma, social support and regimen-specific support on quality of life in adult patients with epilepsy. *Health education research*,*25*(4), 575-584.

WHO (2015. http://www.who.int/mediacentre/factsheets/fs999/en/

Wilson, I. B., & Cleary, P. D. (1995). Linking clinical variables with health-related quality of life: a conceptual model of patient outcomes. *Jama*, *273*(1), 59-65.

Wong, J. P. H., & Poon, M. K. L. (2010). Bringing translation out of the shadows: translation as an issue of methodological significance in cross-cultural qualitative research. *Journal of Transcultural Nursing*, *21*(2), 151-158.

Wood, D. M., Looker, J. J., Shaikh, L., Button, J., Puchnarewicz, M., Davies, S., ... & Dargan, P. I. (2009). Delayed onset of seizures and toxicity associated with recreational use of Bromo-dragonFLY. *Journal of Medical Toxicology*, *5*(4), 226-229.

World Health Organisation (2010). Epilepsy in the WHO Eastern Mediterranean Region.

World Health Organisation. (2003). Adherence to long-term therapies: Evidence for Action.

World Health Organization. (2001). *The World Health Report 2001: Mental health: new understanding, new hope*. World Health Organization.

World Health Organization. (2007). *International Classification of Functioning, Disability, and Health: Children & Youth Version: ICF-CY*. World Health Organization.

Wright, T. (2014). Managing gendered expectations upon resettlement: the experiences of Iraqi Kurdish Muslim women in the UK. *Gender, Place & Culture*, *21*(6), 733-749.

Yang, L. H., Kleinman, A., Link, B. G., Phelan, J. C., Lee, S., & Good, B. (2007). Culture and stigma: Adding moral experience to stigma theory. *Social science & medicine*, *64*(7), 1524-1535.

Yaremko, R. M. (1986). *Handbook of research and quantitative methods in psychology: For students and professionals*. Psychology Press.

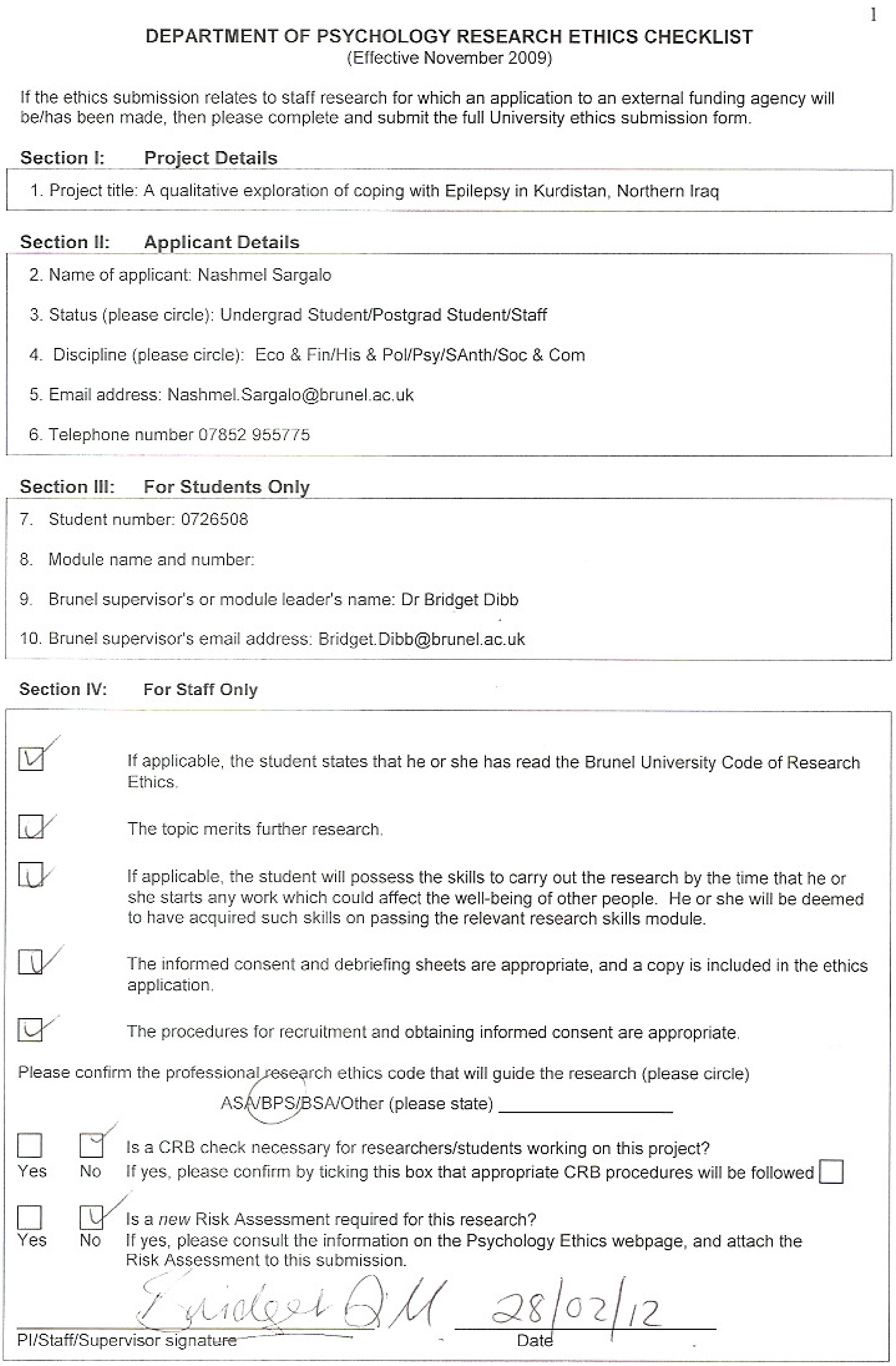
Youn, S. Y., Hong, S. B., & Kwak, J. K. (2001). The relationship of stigma and quality of life in patients with epilepsy. *Journal of Korean Epilepsy Society*,*5*(2), 172-176.

Young, G. B., Derry, P., Hutchinson, I., John, V., Matijevic, S., Parrent, L., & Wiebe, S. (2002). An epilepsy questionnaire study of knowledge and attitudes in Canadian college students. *Epilepsia*, *43*(6), 652-658.

Yue, L., Yu, P. M., Zhao, D. H., Wu, D. Y., Zhu, G. X., Wu, X. Y., & Hong, Z. (2011). Determinants of quality of life in people with epilepsy and their gender differences. *Epilepsy & Behavior*, *22*(4), 692-696.

Chapter 10: Appendices

10.1. Brunel Ethics Form



1

DEPARTMENT OF PSYCHOLOGY RESEARCH ETHICS CHECKLIST

(Effective November 2009)

If the ethics submission relates to staff research for which an application to an external funding agency will be/has been made, then please complete and submit the full University ethics submission form.

Section I: Project Details

1. Project title: A qualitative exploration of coping with Epilepsy in Kurdistan, Northern Iraq

Section II: Applicant Details

2. Name of applicant: Nashmel Sargalo

3. Status (please circle): Undergrad Student/Postgrad Student/Staff

4. Discipline (please circle): Eco & Fin/His & Pol/Psy/SAnth/Soc & Com

5. Email address: Nashmel.Sargalo@brunel.ac.uk

6. Telephone number 07852 955775

Section III: For Students Only

7. Student number: 0726508

8. Module name and number:

9. Brunel supervisor's or module leader's name: Dr Bridget Dibb

10. Brunel supervisor's email address: Bridget.Dibb@brunel.ac.uk

Section IV: For Staff Only

☑ If applicable, the student states that he or she has read the Brunel University Code of Research Ethics.

☑ The topic merits further research.

☑ If applicable, the student will possess the skills to carry out the research by the time that he or she starts any work which could affect the well-being of other people. He or she will be deemed to have acquired such skills on passing the relevant research skills module.

☑ The informed consent and debriefing sheets are appropriate, and a copy is included in the ethics application.

☑ The procedures for recruitment and obtaining informed consent are appropriate.

Please confirm the professional research ethics code that will guide the research (please circle)

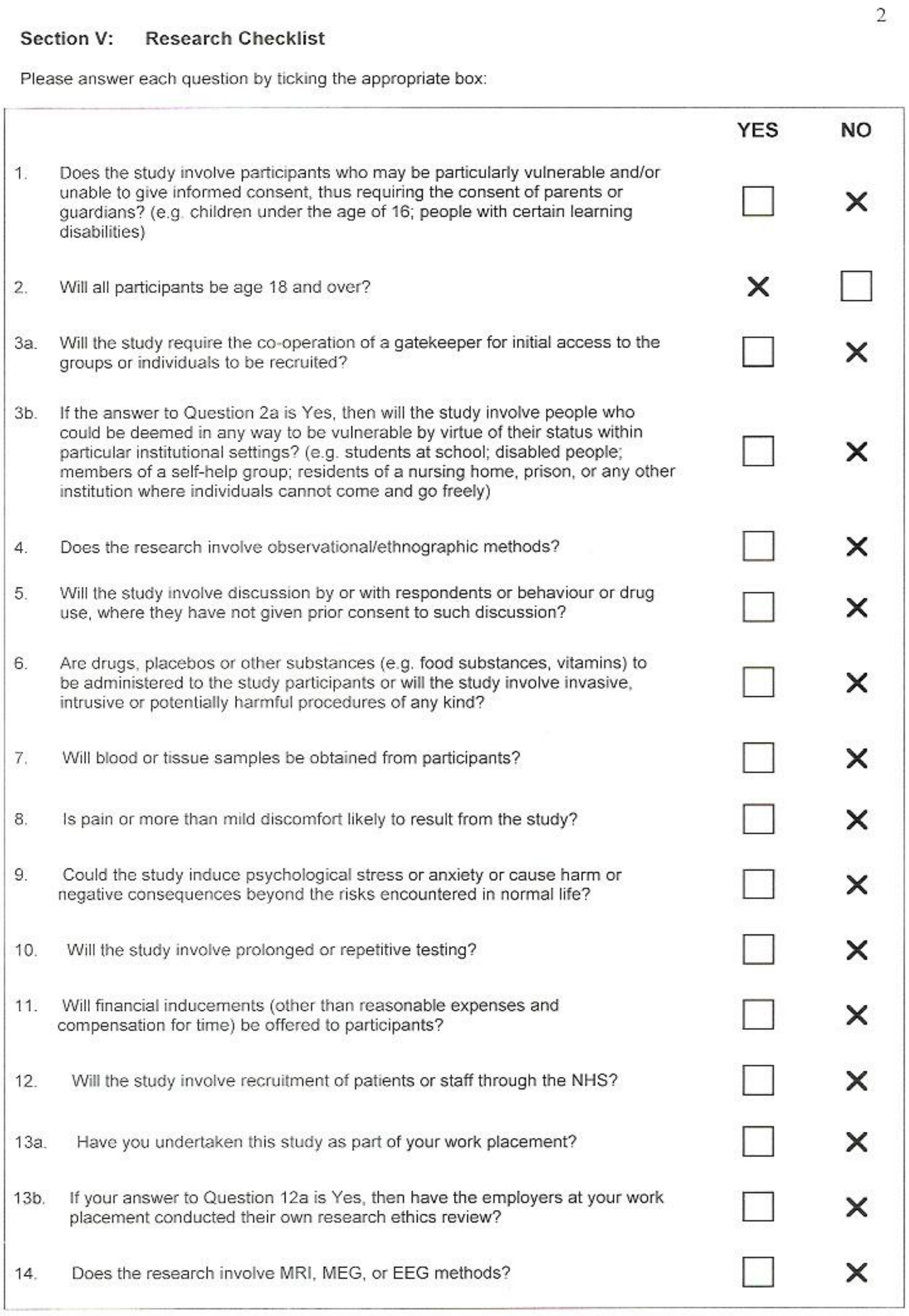
ASA/[✓ BPS]/BSA/Other (please state) ____________

☐ Yes ☑ No Is a CRB check necessary for researchers/students working on this project?
If yes, please confirm by ticking this box that appropriate CRB procedures will be followed ☐

☐ Yes ☑ No Is a *new* Risk Assessment required for this research?
If yes, please consult the information on the Psychology Ethics webpage, and attach the Risk Assessment to this submission.

Bridget ____________ 28/02/12

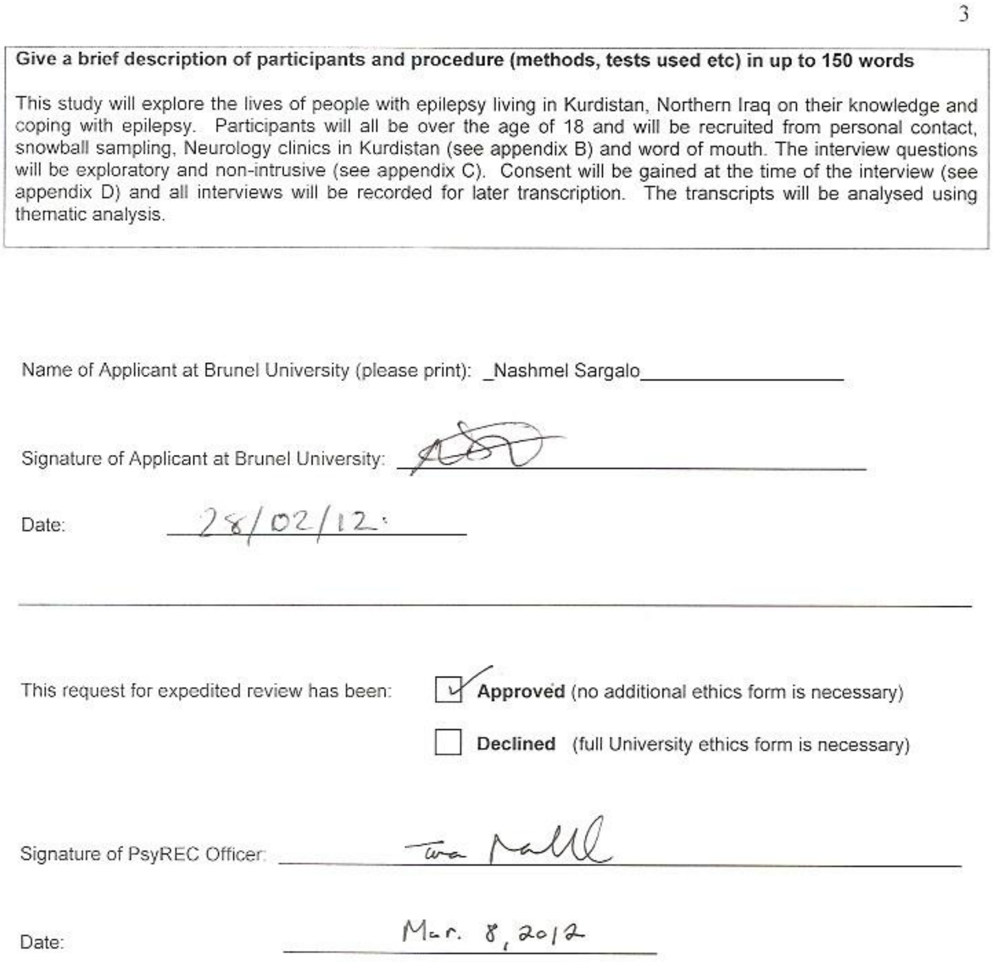
PI/Staff/Supervisor signature Date



Section V: Research Checklist

Please answer each question by ticking the appropriate box:

		YES	NO
1.	Does the study involve participants who may be particularly vulnerable and/or unable to give informed consent, thus requiring the consent of parents or guardians? (e.g. children under the age of 16; people with certain learning disabilities)	☐	☒
2.	Will all participants be age 18 and over?	☒	☐
3a.	Will the study require the co-operation of a gatekeeper for initial access to the groups or individuals to be recruited?	☐	☒
3b.	If the answer to Question 2a is Yes, then will the study involve people who could be deemed in any way to be vulnerable by virtue of their status within particular institutional settings? (e.g. students at school; disabled people; members of a self-help group; residents of a nursing home, prison, or any other institution where individuals cannot come and go freely)	☐	☒
4.	Does the research involve observational/ethnographic methods?	☐	☒
5.	Will the study involve discussion by or with respondents or behaviour or drug use, where they have not given prior consent to such discussion?	☐	☒
6.	Are drugs, placebos or other substances (e.g. food substances, vitamins) to be administered to the study participants or will the study involve invasive, intrusive or potentially harmful procedures of any kind?	☐	☒
7.	Will blood or tissue samples be obtained from participants?	☐	☒
8.	Is pain or more than mild discomfort likely to result from the study?	☐	☒
9.	Could the study induce psychological stress or anxiety or cause harm or negative consequences beyond the risks encountered in normal life?	☐	☒
10.	Will the study involve prolonged or repetitive testing?	☐	☒
11.	Will financial inducements (other than reasonable expenses and compensation for time) be offered to participants?	☐	☒
12.	Will the study involve recruitment of patients or staff through the NHS?	☐	☒
13a.	Have you undertaken this study as part of your work placement?	☐	☒
13b.	If your answer to Question 12a is Yes, then have the employers at your work placement conducted their own research ethics review?	☐	☒
14.	Does the research involve MRI, MEG, or EEG methods?	☐	☒



Give a brief description of participants and procedure (methods, tests used etc) in up to 150 words

This study will explore the lives of people with epilepsy living in Kurdistan, Northern Iraq on their knowledge and coping with epilepsy. Participants will all be over the age of 18 and will be recruited from personal contact, snowball sampling, Neurology clinics in Kurdistan (see appendix B) and word of mouth. The interview questions will be exploratory and non-intrusive (see appendix C). Consent will be gained at the time of the interview (see appendix D) and all interviews will be recorded for later transcription. The transcripts will be analysed using thematic analysis.

Name of Applicant at Brunel University (please print): _Nashmel Sargalo__________________

Signature of Applicant at Brunel University: ______________________

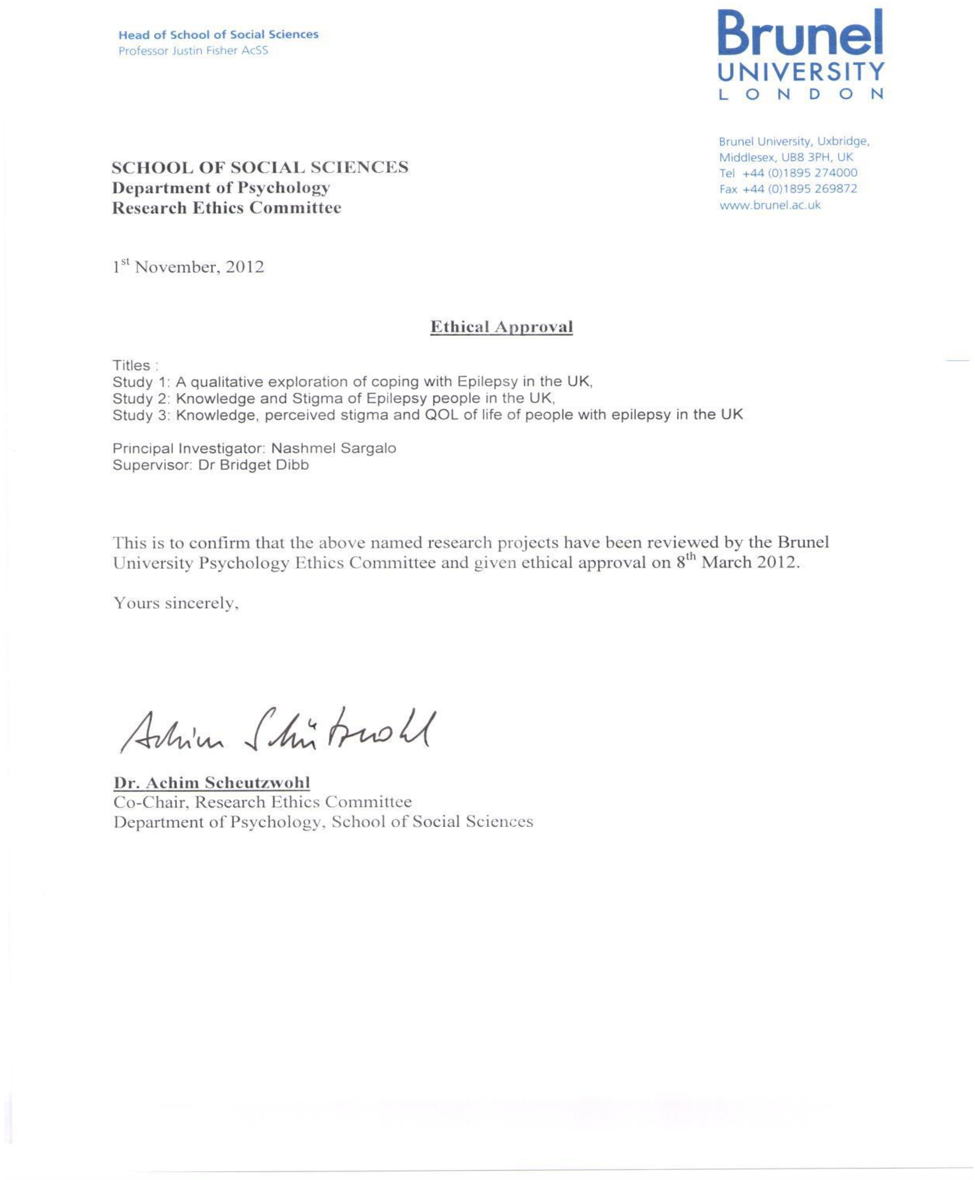
Date: 28/02/12.

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: Mar. 8, 2012



Head of School of Social Sciences
Professor Justin Fisher AcSS

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SCHOOL OF SOCIAL SCIENCES
Department of Psychology
Research Ethics Committee

1st November, 2012

Ethical Approval

Titles :
Study 1: A qualitative exploration of coping with Epilepsy in the UK,
Study 2: Knowledge and Stigma of Epilepsy people in the UK,
Study 3: Knowledge, perceived stigma and QOL of life of people with epilepsy in the UK

Principal Investigator: Nashmel Sargalo
Supervisor: Dr Bridget Dibb

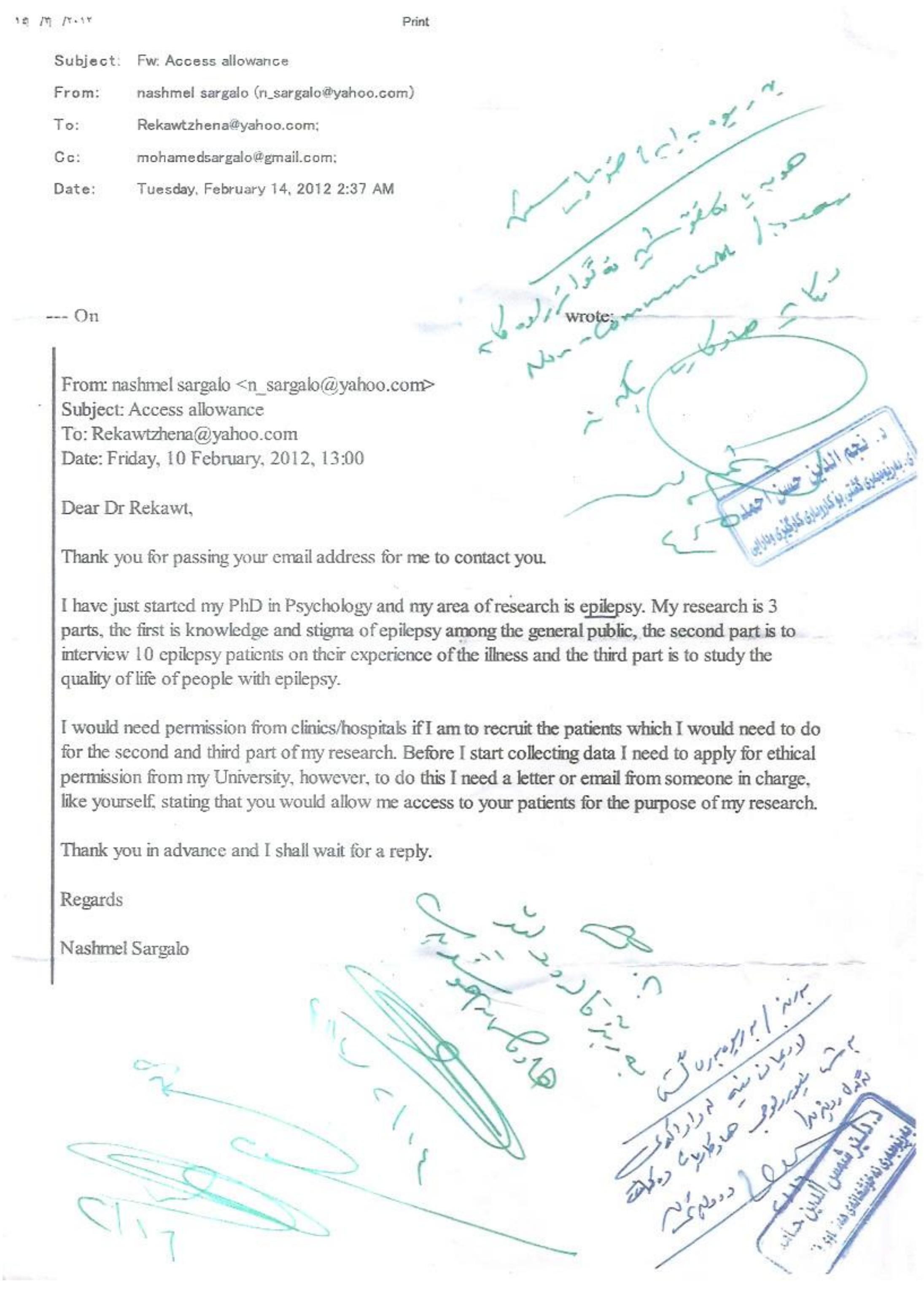
This is to confirm that the above named research projects have been reviewed by the Brunel University Psychology Ethics Committee and given ethical approval on 8th March 2012.

Yours sincerely,

Achim Schützwohl

Dr. Achim Scheutzwohl
Co-Chair, Research Ethics Committee
Department of Psychology, School of Social Sciences

10.2. Kurdistan Permission to Carry out Research in Neurology Clinic



١٥ /٣ /٢٠١٢ Print

Subject: Fw: Access allowance
From: nashmel sargalo (n_sargalo@yahoo.com)
To: Rekawtzhena@yahoo.com;
Cc: mohamedsargalo@gmail.com;
Date: Tuesday, February 14, 2012 2:37 AM

--- On wrote:

From: nashmel sargalo <n_sargalo@yahoo.com>
Subject: Access allowance
To: Rekawtzhena@yahoo.com
Date: Friday, 10 February, 2012, 13:00

Dear Dr Rekawt,

Thank you for passing your email address for me to contact you.

I have just started my PhD in Psychology and my area of research is epilepsy. My research is 3 parts, the first is knowledge and stigma of epilepsy among the general public, the second part is to interview 10 epilepsy patients on their experience of the illness and the third part is to study the quality of life of people with epilepsy.

I would need permission from clinics/hospitals if I am to recruit the patients which I would need to do for the second and third part of my research. Before I start collecting data I need to apply for ethical permission from my University, however, to do this I need a letter or email from someone in charge, like yourself, stating that you would allow me access to your patients for the purpose of my research.

Thank you in advance and I shall wait for a reply.

Regards

Nashmel Sargalo

[illegible] Non-Communicable [illegible]

د. نجم الدين حسن احمد
بەڕێوەبەری گشتی بۆ کاروباری کارگێڕی و دارایی

[illegible]

د. دلێر شمس الدين

10.3. Interview Schedule English

Demographics:

1. How old are you?
2. What is your marital status?
3. Do you have any dependants?
4. What is your occupation?
5. How long have you had epilepsy?
6. Do you know other people with epilepsy?
7. Tell me the circumstances around your diagnosis.
8. How did you feel when you were first diagnosed?
9. What was your knowledge of epilepsy before your diagnosis?
10. How confident are you that you have good knowledge of epilepsy?
11. What type of support did you get from your family/friends?
12. How are you now? Do you have regular seizures?
13. Explain how you feel before a seizure.
14. Explain to me the circumstances of your seizures; is there anything that you feel triggers an attack?
15. How do you feel after an epileptic seizure?
16. What do those around you do when you have a seizure?
17. What do you think people feel when they see you have a seizure? How does that make you feel?
18. Do you feel that you have any control over your seizures? If so how?
19. How did you begin to cope with being epileptic?
20. Do you feel that you can tell people about having epilepsy? Please explain.
21. How has your life changed because of epilepsy?
22. How has epilepsy affected your outlook on life?

23. How do you feel about your life?

24. Do you feel having epilepsy changed your life? If so please explain.

25. How would people treat you if they knew of your epilepsy?

26. Is there anything you can’t do because of your epilepsy?

27. How is epilepsy perceived in your culture?

28. What is the most difficult aspect of having epilepsy?

29. What is your advice to those who are newly diagnosed? What would you advise them on how to cope?

30. What changes would you recommend to help those who have epilepsy to make their life easier? This could be anything that you feel strongly about.

31. Do you have anything to add?

32. What are you plans and aspirations for the future?

    Thank participant for taking part and give contact details in case they have any questions.

10.4. Interview Schedule Kurdistan

1. تەمەنت چەندە؟
2. باری خێزانیت چی یە؟
3. کەس هەیە پشتت پێ ببەستێ(وەکو منداڵ)؟
4. پیشە(کارت) چی یە؟
5. لەکەیەوە پەرکەمت هەیە؟
6. کەسی تر دەناسیت کە پەرکەمی هەبێت؟
7. بارودۆخی دەستنیشان کردنی نەخۆشی پەرکەمەکەتم بۆ ڕوون بکەرەوە
8. هەستت بە چی کرد کە یەکەم جار پەرکەمت تیا دەستنیشان کرا؟
9. زانیاریت چی بوو دەربارەی پەرکەم پیش ئەوەی نەخۆشی یەکەت تیا دەستنیشان بکرێ، بە بەراوردکردن بە ئێستا؟
10. چەند متمانەت بەخۆتە کە زانیاری تەواو ت هەیە دەربارەی پەرکەم؟
11. چ جۆرە یارمەتی یەکت دراوە لە لایەن خێزان و هاوڕێکانتەوە؟
12. ئێستا چۆنیت؟ ئایا زوو زوو تووشی بورانەوە دەبیت؟
13. ڕوونی بکەرەوە هەستت چۆنە پێش بووڕانەوە؟
14. بارودۆخی بوورانەوەکانتم بۆ ڕوون بکەرەوە؛ ئایا هیچ شتێك هەیە کە تۆ هەست بکەیت دەست پێکەری هێرش(بورانەوە)کان بێت؟
15. هەست بەچی دەکەیت دوای بووڕانەوە؟
16. دەتوانیت پێم بڵێی ئەوانەی لە دەوروبەرتن چی دەکەن کاتێك تۆ دەبووێیتەوە؟
17. پێت وایە خەڵك هەست بەچی دەکەن کە تۆ دەبینن دەبووێیتەوە(فێت لێ دێ)؟ئەوە وات لێ دەکات هەست بە چی بکەیت؟
18. تۆ پێت وایە هیچ جۆرە کۆنترۆڵێکت هەیە بەسەر بوورانەوەکانتدا؟ئەگەر وایە چۆن؟
19. چۆن دەستت بەوەکرد کە مامەڵە لەگەڵ ئەو ڕاستی یەدا بکەی کە تۆ تووشبووی پەرکەمیت؟
20. هەست دەکەیت بتوانیت بە خەڵك بڵێ ی کە پەرکەمت هەیە؟تکایە ڕوونی بکەرەوە...
21. ژیانت چۆن گۆڕاوە بەهۆی نەخۆشی پەرکەمەکەتەوە؟
22. پەرکەم چۆن کاریگەری هەبووە لەسەر تێڕوانین(بۆچوونی) تۆ بۆ ژیان؟
23. هەستت چۆنە بەرامبەر ژیانت؟
24. هەستت چی یە کە بەهۆی بوونی پەرکەمەوە ژیانت گۆڕاوە؟ئەگەر وایە تکایە ڕوونی بکەرەوە..
25. خەڵکی چۆن مامەڵەت لەگەڵ دەکەن ئەگەر بزانن کە پەرکەمت هەیە؟
26. ئایا هیچ شتێك هەیە کە نەتوانیت بیکەیت بەهۆی پەرکەمەکەتەوە؟
27. لە کەلتور(داب و نەریت)ی ئێوەدا، پەرکەم چۆن قبوڵ دەکرێت (یا وەردەگیرێت)؟
28. ئایا قورسترین ڕواڵەت بۆ تووش بوون بە پەرکەم چی یە؟
29. ئامۆژگارییت چی یە بۆ ئەو کەسانەی کە تازە نەخۆشی یەکەیان تیا دیاری کراوە؟ئامۆژگاری تۆ چی یە بۆچۆنییەتی مامەڵەکردن لەگەڵیدا؟
30. چ جۆرە گۆڕانکارییەك پێشنیار دەکەیت تا یارمەتی ئەو کەسانەی بدەی کە پەرکەمیان هەیە تا ژیانیان ئاسانتر بکات؟ئەمە لەوانەیە هەر شتێك بێت کە تۆ باوەڕێکی پتەوت پێی هەیە.
31. هیچ شتێکی ترت هەیە کە زیادی بکەیت؟
32. پلان و ئامانجەکانت چین بۆ داهاتوو؟

- سوپاسی بەشداربوو بکە بۆ بەشداربوونی و زانیاری پەیوەندی کردنیان پێ بدە، نەوەك پرسیارێکیان هەبێ.

10.5. Consent Form UK – Study 1 – Qualitative Method

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A qualitative exploration of coping with Epilepsy in the UK

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 ‘‘A qualitative exploration of coping with Epilepsy in the UK’’ to be conducted at Brunel University, with ‘‘Nashmel Sargalo’’ as principal investigator. The broad goal of this research program is to explore your experiences and your feelings about having epilepsy. Specifically, I have been told that I will be asked to take part in an interview. This session should take no longer than one hour 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 a better understanding of my experience of epilepsy in general – not any particular individual’s personal knowledge and views 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 Nashmel Sargalo at nashmel.sargalo@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 or Dr Tara Marshall at 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 Name	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 Name	Date

10.6. Debriefing Form UK – Study 1 – Qualitative Method

A qualitative exploration of coping with Epilepsy in the UK

The aim of this study is to explore how people in the UK cope with epilepsy diagnosis.

This study has tried to explore individual's perspective on their diagnosis and what coping strategies have been adopted to deal with epilepsy. This is all explored in relation to the culture and knowledge of individuals.

If you would like to have more information about this area of research please refer to the following articles:

1) ''Quantitative Assessment of seizure Severity for Clinical Trials: A review of Approaches to Seizure Components'' by Cramer and French (2001), *Epilepsia*, **42**(1):119-129.

2) ''Cross-cultural Differences in Levels of Knowledge about Epilepsy'' by Doughty et al (2003), Epilepsia, **44**(1): 115-123.

3) ''Social and Family characteristics of Hispanic with epilepsy'' by Chong et al (2011), *Seizure*, **21**(2012) 12-16

4) For more information on epilepsy please see the link below:

   http://www.epilepsy.org.uk/

Thank you again for taking part in this important study.

10.7. Consent Form Kurdistan - Study 1- Qualitative Method

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بەدواداگەڕانێکی چۆنێتی(جۆرێتی) بۆ مامەڵەکردن لە گەڵ نەخۆشی پەرکەم(فێ) لە ناو خەڵکانی کورد لە
کوردستان/باکوری عیراق

بەشی دەروونناسی لە زانکۆی برونێڵ داواکارە لە هەموو ئەوکەسانەی کە بەشداری دەکەن لە لێکۆڵینەوەی دەروونناسی
دا،ڕێپێدان و ڕازیبوونی خۆیان دەربڕن بۆ ئەنجامدانی ئەم کارە.تکایە ئەم نوسراوەی خوارەوە بخوێنەرەوە و ئیمزای
بکە ئەگەر ڕازییت بە ناوەڕۆکەکەی.

من بە ئارەزووی خۆم و خۆبەخشانە ڕازیم کە بەشداری بکەم لەم پرۆژەی لێکۆڵینەوەیە بەناونیشانی(بەدواداگەڕانێکی
چۆنێتی(جۆرێتی) بۆ مامەڵەکردن لە گەڵ نەخۆشی پەرکەم(فێ) لە ناو خەڵکانی کورد لە کوردستان/باکوری عیراق) کە
لە لایەن زانکۆی برونێڵ ئەنجام دەدرێ بە سەرپەرشتی " نەشمیل سەرگەڵویی" وەك بەرپرسی لێکۆڵەرەوە. ئامانجی
بەرفراوانی ئەم پرۆگرامی لێکۆڵینەوەیە بۆ دۆزینەوە وگەڕانە بەدوای بەسەرهاتەکانی تۆ و هەست دەربڕینەکانی تۆ
بەرامبەر تووشبوونت بە نەخۆشی پەرکەم. بە تایبەتیش پێم ووتراوە کە کە داوام لێ دەکرێ کە ڕاپرسییەك پڕبکەمەوە.
ئەم بەشە لە٦٠ دەقیقە زیاتر ناخایەنێت بۆ تەواوکردن.

پێم ڕاگەیەنراوە کە وەڵامەکانم بە تەواوەتی بە شێوەیەکی نهێنی دەمێنێتەوە. ئەوەش دەزانم کە لە هەرکاتێکی
پڕکردنەوەی ئەم فۆرمەدا من ئازادم کە بڵێم ناتوانم یان نامەوێت بەردەوام بم، من ئازادم وازبێنم بێ هیچ دەرئەنجامێکی
سەلبی و خراپ. بەشداری کردنیشم لەم لێکۆڵینەوەیەدا بە تەواوەتی خۆبەخشانەیە و لەوانەیە لەهەرکاتێکدا پاشەکشێ
بکەم. پاشەکشەکردنم نابێتەهۆی هیچ سزایەکی ئەکادیمی یان هەرجۆرێکی تر. ناوم پەیوەست ناکرێ بە بابەتەکانی
لێکۆڵینەوەکە، چونکە لێکۆڵەرەوەکە دەیەوێت کە باشتر تێ بگات لە ئەزمون و بەسەرهاتەکانی من لەگەڵ نەخۆشی
پەرکەم بەگشتی- نەك زانیاری شخصی وبۆچوونی تاکەکەسێك بە تایبەتی. ڕێگام پێدراوە کە پرسیاربکەم لە بارەی
شێوازوڕێگەی لێکۆڵینەوەکە و وەك پێویست وەڵامم دراوەتەوە. پێم ووتراوە کەهەر پرسیارێکم هەیە بە گشتی لە بارەی
کە پەیوەندی بە پرۆژەکەوە هەیە، دەتوانم ئازادانە پەیوەندی بکەم بە نەشمیل   ئەم پرۆژەیە یان کێشەیەکی ڕەوشتی
. ئەگەر هەر گلەیی یان ڕەخنەیەکم هەبێ لەبارەی nashmel.sargalo@brunel.ac.uk سەرگەڵویی لە ڕێگای
شێوازی بەڕێوەچوونی لێکۆڵینەوەکە یان بە ئەنجام گەیاندنی دەتوانم پەیوەندی بکەم بە یەکێك لە بەرپرسانی لێکۆڵینەوەی
Tara یان دکتۆر taeko.wydell@brunel.ac.uk لە ڕێگای Taeko Wydell دەروونناسی پرۆفیسۆر
. tara.marshall@brunel.ac.uk لە ڕێگای Marshall

ئەم ڕێ پێدانی بەشداربوونەی سەرەوەم خوێندەوە و تێیگەیشتم. ئیمزاکەم ئیمزاکەم نابێتە هۆی دەستبەرداربوونم لە مافە
یاسایی یەکانم. دواتریش دەتوانم کە کۆپییەکی ئەم فۆرمە وەك تۆمارێك لای خۆم هەڵگرم.

....

ئیمزای بەشداربوو ناوی بەشداربوو بەروار

به دوورودرێژی شێوازی لێکۆڵینەوەکەم شی کردەوە و پێناسە کرد بۆ ئەم بەشداربووەی لای سەرەوە و ئەویش ڕازیی بوو کە بەشداری بکات. دواتریش دەتوانم کە کۆپییەك لەم نوسراوی ڕێ پێدانە وەك تۆمارێك لای خۆم هەڵگرم.

....	....	....
ئیمزای سەرپەرشتیاری لێکۆڵەرەوە	ناوی لێکۆڵەرەوە	بەروار

10.8. Debriefing Form Kurdistan– Study 1- Qualitative Method

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بەدواداگەڕانێکی جۆرێتی(چۆنێتی) بۆ مامەڵەکردن لە گەڵ نەخۆشی پەرکەم(فێ) لە ناو خەڵکانی کورد لە کوردستان/باکوری عیراق

ئامانجی ئەم توێژینەوەیە بۆ گەڕانە بەدوای چۆنیەتی مامەڵەکردنی خەڵکی کوردستان/باکوری عیراق ە لەکاتی دیاری کردنیان بە نەخۆشی پەرکەم.

ئەم توێژینەوەیە هەوڵیدا بەرچاوگرتنی تاکی کۆمەڵگا بدۆزێتەوە لە کاتی دیاری کردنیان بە نەخۆشی پەرکەم و چ مامەڵەکردنێکی ستراتیجی خراوەتەکار بۆ هەڵسوکەوتکردن لەگەڵ نەخۆشی پەرکەم دا. لە هەموو ئەوانە گەڕاین کە پەیوەندییان بە داب و نەریت و زانیاری تاکەکانەوە هەیە.

ئەگەر زانیاری زیاترت ویست لەسەر لێکۆڵینەوەکان لەم بوارەدا بگەڕێرەوە بۆ ئەم بابەتانەی لای خوارەوە:

1) ‘‘Quantitative Assessment of seizure Severity for Clinical Trials: A review of Approaches to Seizure Components’’ by Cramer and French (2001), *Epilepsia*, **42**(1):119-129.

2) ‘‘Cross-cultural Differences in Levels of Knowledge about Epilepsy’’ by Doughty et al (2003), Epilepsia, **44**(1): 115-123.

3) ‘‘Social and Family characteristics of Hispanic with epilepsy’’ by Chong et al (2011), *Seizure*, **21**(2012) 12-16

4) بۆ زانیاری زیاتر لەسەر پەرکەم(فێ) بە زمانی کوردی ئەم لینکەی خوارەوە بخوێنەرەوە:

http://www.epilepsy.org.uk/sites/epilepsy/files/epilepsyaction_newtoepilepsy_kurdish.pdf

دووبارە زۆر سوپاس بۆ بەشداربوونت لەم توێژینەوە گرنگەدا

10.9. Questionnaire People with Epilepsy UK – Study 2

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Hello, thank you for agreeing to take part in this questionnaire. The following questions are about you, please answer as truthfully as you can. There are no right or wrong answer, I am only interested in your views.

Age: Gender (please tick one): Male ☐ Female ☐

Marital Status (please tick one): Single ☐ Married ☐ Divorced ☐ Widowed ☐

Occupation:

Highest Educational Qualification:

Country/Town of Birth:

Country/Town of Residence (if different from above):

Time at Place of Residence:

Have you been diagnosed with epilepsy? Yes ☐ No ☐

When were you diagnosed with epilepsy?

SECTION A

The following statements contain information about epilepsy, please decide whether you think the statement is TRUE or FALSE and tick accordingly

	Statements	TRUE	FALSE
1	Epilepsy is always caused by brain damage		
2	Epilepsy is not infectious		
3	Epilepsy is a symptom of mental illness		
4	All people with epilepsy have similar symptoms		

5	Almost anyone can have a seizure given the appropriate circumstances		
6	An EEG can be used to help diagnose epilepsy		
7	If an EEG is abnormal, this is a definite sign of epilepsy		
8	An EEG is designed to detect electrical activity from the brain		
9	All people with epilepsy lose consciousness during seizures		
10	An epileptic seizure can be described as a temporary lack of oxygen to the brain		
11	Some seizures may last for a matter of seconds and not be noticed by others		
12	All seizures affect both sides of the brain		
13	Certain forms of brain damage always cause epilepsy		
14	A normal EEG means that you do not have epilepsy		
15	For most people, doctors can effectively treat epilepsy with drugs		
16	All those who start drugs for their epilepsy have to take them for life		
17	Increasing the dose of antiepileptic drugs increases the chances of side effects		
18	An epileptic seizure can be described as an abnormality in the function of nerve cells in the brain		
19	For antiepileptic drugs to be successful, they must be taken regularly		
20	If you forget to take antiepileptic drug for a day, it is usually OK to take two doses together		
21	Some people get a warning or feeling shortly before a seizure		
22	Blood samples can be used to measure the concentrations of antiepileptic drugs in the system		
23	People taking a combination of antiepileptic drugs are more likely to have side effects than those taking only one		
24	Most people’s seizures are well controlled soon after starting regular drug treatment		
25	It is always helpful to take extra doses of antiepileptic drugs when not feeling well		
26	If seizures stop with antiepileptic drugs, this means your epilepsy been cured		
27	Few people with a diagnosis of epilepsy are taking antiepileptic drugs		
28	Some people have been taught to control their seizures by psychological methods		
29	There is no need to continue taking antiepileptic drugs if your seizures stop		
30	Brain surgery is still used as a method of preventing seizures		

31	Most mothers taking antiepileptic drugs are able to breastfeed		
32	Too much alcohol may make seizures more likely		
33	Most seizures result in brain damage		
34	Stress may cause some seizures		

SECTION B

The following questions are on how often you experience symptoms of epilepsy. Please read the following questions and tick on the scale where it is most true for you.

		Daily	Less than daily but more than once a week	Less than once a week to more than once a month	Less than once a month to more than once a year	Less than once a year
1	How frequently do you have seizure? (please tick one)					

PLEASE COMPLETE THE FOLLOWING QUESTIONS THINKING ABOUT THE MOST SEVERE SEIZURE YOU EXPERIENCED DURING THE <u>PAST 4 WEEKS.</u>

2) How many seizures have you experienced during the past 4 weeks? __________ Seizures

(Please enter '0' if you have not experienced any seizures in the last 4 weeks. If you cannot remember, please estimate based on the number you usually had during a day or week.)

		Very Severe	Severe	Mild	Very Mild
3	I feel that my most severe seizures have mostly been:				

		I blank out for less than 1 minute	I blank out for between 1 and 2 minutes	I blank out for between 3 and 5 minutes	I blank out for more than 5 minutes	I never blank out/lose consciousness
4	Most commonly when I blank					

	out/lose consciousness:					

		Always	Usually	Sometimes	Never
5	When I have most severe seizures, I smack my lips, fidget or behave in an unusual way:				

		I feel very confused	I feel fairly confused	I feel slightly confused	I do not feel confused
6	After my most severe seizures:				

		Less than 1 minute	Between 1 and 5 minutes	Between 6 minutes and 1 hour	Between 1 and 2 hours	More than 2 hours	I never feel confused
7	After my most severe seizures, my confusion lasts for:						

		I always fall to the ground	I usually fall to the ground	I sometimes fall to the ground	I never fall to the ground
8	When I have my most severe seizures:				

		I always have a headache	I usually have a headache	I sometimes have a headache	I never have a headache
9	After my most severe seizures:				

		I always feel sleepy	I usually feel sleepy	I sometimes feel sleepy	I never feel sleepy
10	After my most severe seizures:				

		I always find that I have wet myself	I usually find that I have wet myself	I sometimes find that I have wet	I never find that I have

				myself	wet myself
11	After my most severe seizures:				

		I always find that I have bitten my tongue	I usually find that I have bitten my tongue	I sometimes find that I have bitten my tongue	I never find that I have bitten my tongue
12	After my most severe seizures:				

		I always find that I have injured myself	I usually find that I have injured myself	I sometimes find that I have injured myself	I never find that I have injured myself
13	After my most severe seizures:				

		Less than 1 minute	Between 1 and 5 minutes	Between 6 minutes and 1 hour	Between 1 to 2 hours	More than 2 hours
14	After most severe seizures(other than biting my tongue) I can usually return to doing what I am doing in:					

SECTION C

Please read the following statements and tick on the scale where you feel you most agree/disagree with the statement.

	Statements	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
1	I have been discriminated against in education because of my epilepsy					
2	Sometimes I feel that I am being talked down to because of my epilepsy					
3	Having epilepsy has made me a more understanding person					
4	I do not feel bad about having epilepsy					
5	I worry about telling people I receive epilepsy treatment					

6	Some people with epilepsy are dangerous					
7	People have been understanding of my epilepsy					
8	I have been discriminated against by police because of my epilepsy					
9	I have been discriminated against by employers because of my epilepsy					
10	My epilepsy has made me more accepting of other people					
11	Very often I feel alone because of my epilepsy					
12	I am scared of how other people will react if they find out about my epilepsy					
13	I would have had a better chances in life if I had not had epilepsy					
14	I do not mind people in my neighbourhood knowing I have epilepsy					
15	I would say I have epilepsy if I was applying for a job					
16	I worry about telling people about my epilepsy					
17	People's reaction to my epilepsy make me keep myself to myself					
18	I am angry with the way people react to my epilepsy					
19	I have not had any trouble from people because of my epilepsy					
20	I have been discriminated against by health professionals because of my epilepsy					
21	People have avoided me because of my epilepsy					
22	People have insulted me because of my epilepsy					
23	Having epilepsy has made me a stronger					

	person					
24	I do not feel embarrassed because of my epilepsy					
25	I avoid telling people about my epilepsy					
26	Having had epilepsy makes me feel life is unfair					
27	I feel the need to hide my epilepsy from my friends					
28	I find it hard telling people I have epilepsy					

SECTION D

The following questions are on the how epilepsy has affected your life. Please circle the number that best corresponds to your views:

1) How does your epilepsy affect your life?
No affect
Severely at all affects my life

0 1 2 3 4 5 6 7 8 9 10

2) How long do you think your epilepsy will continue?
A very
Forever short time

0 1 2 3 4 5 6 7 8 9 10

3) How much control do you feel you have over your epilepsy?
Absolutely Extreme
no control amount of control

0 1 2 3 4 5 6 7 8 9 10

4) How much do you think your treatment can help your epilepsy?
Not at all Extremely
helpful

0 1 2 3 4 5 6 7 8 9 10

5) How much do you experience symptoms from your illness?
No symptoms at all — Many severe symptoms

0 1 2 3 4 5 6 7 8 9 10

6) How concerned are you about your illness?
Not at all concerned — Extremely concerned

0 1 2 3 4 5 6 7 8 9 10

7) How well do you feel you understand your epilepsy?
Don't understand at all — Understand very clearly

0 1 2 3 4 5 6 7 8 9 10

8) How much does your epilepsy affect you emotionally? (e.g. does it make you angry, scared, upset or depressed?)
Not at all affected emotionally — Extremely affected emotionally

0 1 2 3 4 5 6 7 8 9 10

9) Please list in rank-order the three most important factors that you believe caused <u>your epilepsy</u>.
The most important causes for me:-
1)____
2)____
3)____

SECTION E

Below is a list of ways you might have felt or behaved. Please tell me how often you have felt this way during the past week.

	During the past week	Rarely or none of the time (less than 1 day)	Some or little of the time (1-2 days)	Occasionally or moderate amount of time (3-4 days)	Most or all of the time (5-7 days)
1	I was bothered by things that				

	usually don’t bother me				
2	I did not feel like eating; my appetite was poor				
3	I felt that I could not shake off the blues even with help from my family or friends				
4	I felt that I was just as good as other people				
5	I felt I had trouble keeping my mind on what I was doing				
6	I felt depressed				
7	I felt that everything I did was an effort				
8	I felt hopeful about the future				
9	I thought my life had been a failure				
10	I felt fearful				
11	My sleep was restless				
12	I was happy				
13	I talked less than usual				
14	I felt lonely				
15	People were unfriendly				
16	I enjoyed life				
17	I had crying spells				
18	I felt sad				
19	I felt that people dislike me				
20	I could not get ''going''				

SECTION F

The following questions ask about how epilepsy has affected your life. These questions are about how you have been FEELING and the type of problems you have been having during the past **4 weeks**. For each question, please give the one answer that comes closest to the way you have been feeling.

(Circle one number on each line)

	How much of the time during the past 4 weeks …	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
1	Did you have a lot of **energy**?	1	2	3	4	5	6
2	Have you felt **downhearted and low**?	1	2	3	4	5	6

		A great deal	A lot	Somewhat	Only a little	Not at all
3	How much of the time in the last 4 weeks your epilepsy or antiepileptic drug caused trouble with **driving (or other transportation)**	1	2	3	4	5

	During the past 4 weeks …	Not at all bothersome	Only a little	Somewhat	A lot	Extremely bothersome
4	How much do your **work limitations** bother you?	1	2	3	4	5
5	How much do your **social limitations** bother you?	1	2	3	4	5
6	How much do your **memory difficulties** bother you?	1	2	3	4	5
7	How much do **physical effects** of antiepileptic drugs bother you?	1	2	3	4	5
8	How much do **psychological effects** of antiepileptic drugs bother you?	1	2	3	4	5

		Very afraid	Somewhat afraid	Not very afraid	Not afraid at all
9	How **afraid** are you of having a seizure during the next 4 weeks?	1	2	3	4

10) How has your QUALITY OF LIFE been during the **past 4 weeks** (that is, how have things been going for you)?

Very good: could hardly have been better	**Pretty good**	**Good & bad about equal**	**Pretty bad**	**Very bad: could hardly have been worse**
1	2	3	4	5

Reviewing all the questions you have answered above, consider the overall impact of these problems on your quality of life **in the past 4 weeks**. (Circle one number)

		Not at all	Somewhat	Moderately	A lot	Very much
11	How much does the state of your epilepsy-related quality of life **distress** you overall?	1	2	3	4	5

Considering **ALL** the questions you have answered, please **indicate the areas** related to your epilepsy that are most **IMPORTANT** to you **NOW**

12) Number the following topics from ‘1’ to ‘7’ with ‘1’ corresponding to the most important topic and ‘7’ to the least important one. Please use each number only once.

☐ **A.** Energy (tiredness)

☐ **B.** Emotion (mood)

☐ **C.** Daily activities (Work, driving, social & other activities)

☐ **D.** Mental function (thinking, concentrating, memory)

☐ **E.** Medication effects (physical, mental)

☐ **F.** Worry about seizures (impact of seizures)

☐ **G.** Overall quality of life

Thank you again for taking part in this questionnaire**,** if you would like to make any comments about this questionnaire or epilepsy please use the space below.

I am interested in asking some more questions in about 10-12 months' time, please tick whether you happy for me to contact ☐ YES ☐ NO

If you have ticked yes, please provide your contact details below:

Name:

Telephone number:

E-mail:

10.10. Questionnaire People with Epilepsy Kurdish – Study 2

سڵاو، سوپاس کە ڕازی بوویت کە بەشداری بکەیت لەم ڕاپرسی یەدا. ئەم پرسیارانەی لای خوارەوە لەبارەی تۆوەیە، تکایە چەندی توانیت بە ڕاستگۆیی وەڵامیان بدەرەوە. هیچ وەڵامێکی غەڵەت یان ڕاست ی تێدا نی یە، من تەنها ئارەزوومەندم کە ڕاو بۆچوونەکانی تۆ بزانم.

تەمەن: ڕەگەز: ☐ نێر   ☐مێ

باری خێزانی(هاوسەرگیری): ☐ تەنیا(زگوردی)   ☐ هاوسەرگیر(خێزاندار) ☐ جیابووەوە ☐ بێوەژن

پیشە:

بەرزترین پلەی خوێندن:

وولات/شاری لە دایك بوون:

وولات/شاری نیشتەجێ بوون(ئەگەرجیاوازە لەگەڵ سەرەوە):

ماوەی نیشتەجێ بوونت لەم شوێنە:

ئایا نەخۆشی پەرکەم ت تیا دیاری کراوە؟   ☐ بەڵێ   ☐ نەخێر

کەی بوو کە نەخۆشی پەرکەمت تیا دەستنیشان کرا؟

بەشی أ

ناوەڕۆکی ئەم دەستەواژانەی لای خوارەوە بریتی یە لە زانیاری دەربارەی پەرکەم، تکایە بڕیار بدە کە کام دەستەواژەیە ڕاستە یان هەڵەیە و نیشانەی بکە:

	دەستەواژەکان	ڕاستە	هەڵەیە
١	پەرکەم هەمیشە بەهۆی تێکچونی مێشکەوە ڕوودەدات		
٢	پەرکەم نەخۆشی یەکی درم نی یە(ناگوێزرێتەوە لە یەکێك بۆ یەکێکی تر)		
٣	پەرکەم نیشانەیەکە بۆ بوونی نەخۆشی دەروونی(مێشکی)		
٤	هەموو ئەو کەسانەی پەرکەمیان هەیە هەمان نیشانەی نەخۆشی یەکەیان هەیە		
٥	نزیکەی هەموو کەسێك ڕێی تێدەچێ ببورێتەوە ئەگەر بارودۆخی گونجاوی بۆ هەڵبکەوێ		

٦	* بەکاربهێنرێت بۆ دیاری کردن و دۆزینەوەی نەخۆشی EEGدەتوانرێت پەرکەم		
٧	نائاسایی بێت، بەدڵنیایی ئەوە نیشانەکی نەخۆشی EEGئەگەر دەرئەنجامی پەرکەمە		
٨	دروستکراوە تاوەکو چالاکی و جموجوڵی کارەبایی لە EEGئامێری مێشکەوە بپشکنێت		
٩	هەموو ئەو کەسانەی کە نەخۆشی پەرکەمیان هەیە لەکاتی بورانەوە(فێ)دا بێ هۆش دەبن		
١٠	بورانەوە(فێ) بەوە پێناسە دەکرێت کە بریتی یە لە کەم چوونی ئۆکسجین بۆ مێشك بە شێوەیەکی کاتی		
١١	هەندێ بورانەوە ماوەی چەند چرکەیەك دەخایەنێ و تێبینی ناکرێ لەلایەن خەڵکی ترەوە		
١٢	هەموو بورانەوەیەك کارلەهەردوو بەشی مێشك دەکات		
١٣	هەندێ شێوازی تێکچوونی مێشك هەمیشە دەبێتە هۆی پەرکەم		
١٤	ئاسایی بێت، مانای وایە نەخۆشی پەرکەمت نی یە EEGئەگەر دەرئەنجامی		
١٥	بۆ زۆربەی خەڵك، دکتۆر دەتوانێ کاریگەرانە چارەسەری پەرکەم بکات بە دەرمان		
١٦	هەموو ئەو کەسانەی کە دەرمان بەکاردەهێنن بۆ پەرکەم دەبێ بۆ هەتا هەتایە بیخۆن		
١٧	زیادکردنی بڕی دەرمانی دژەپەرکەم ئەگەری کاریگەری(زیانی) لاوەکی زیاد دەکات		
١٨	دەتوانرێ پێناسەی بورانەوە(فێ)بکرێ بەوەی کە بارێکی نائاسایی یە لە فەرمانی خانەکانی دەمار لە مێشکدا		
١٩	بۆ دەرئەنجامی باش و سەرکەوتوویی دەرمانی دژەپەرکەم،دەبێ بەردەوام بخورێت		
٢٠	ئەگەر بۆ ڕۆژێك لەبیرت بچێ دەرمانی پەرکەم بخۆیت، ئاسایی یە کە دواتر دوو بڕ بخورێت		
٢١	هەندێك کەس جۆرێك لە ئاگادارکردنەوە یان هەستێکیان دەبێ پێش بورانەوە(فێ)		
٢٢	دەتوانرێت خوێن وەك پێوانەیەك بەکاربهێنرێت بۆ دیاریکردنی خەستی دەرمانی پەرکەم		

	له لەشدا			
٢٣	ئەو کەسانەی دوو جۆر دەرمانی پەرکەم بەکاردێنن، زیاتر بۆی هەیە کاریگەری(زیانی) لاوەکی یان لەسەربێت وەك لەو کەسانەی یەك جۆر بەکاردێنن			
٢٤	بورانەوەی زۆربەی خەڵکانی تووشبوو بە پەرکەم زیاترکۆنترۆڵ دەکریٚ یەکسەر دوای چارەسەری بەردەوام بە دەرمان			
٢٥	هەمیشە یارمەتیدەرترە ئەگەر بڕی زیاتری دەرمانی دژە پەرکەم بخوریٚ کاتێك هەست بە خراپی دەکەیت			
٢٦	ئەگەر بورانەوە(فیٚ)کانت بوەستیٚ پاش بەکارهێنانی دەرمان، مانای وایە پەرکەمەکەت چارەسەربووە			
٢٧	خەڵکێکی کەمی تووشبوو بە پەرکەم، دەرمانی چارەسەری دژە پەرکەم بەکاردێنیٚ، کاتێك دەستنیشانی نەخۆشیەکەی دەکرێت			
٢٨	هەندێك کەس وا فێرکراون کە کۆنترۆڵی بورانەوەکانیان بکەن لەڕێگای ڕێگەچارەی دەروونی یەوە			
٢٩	پێویست ناکات بەردەوام بیت لە خواردنی دەرمانی پەرکەم ئەگەر بورانەوەکانت وەستا			
٣٠	نەشتەرگەری مێشك وەك ڕێگاچارەیەك بەکاردێت بۆ ڕێگرتن لە بورانەوەکان			
٣١	زۆربەی ئەو دایکانەی لەسەر دەرمانی پەرکەمن، دەتوانن شیربدەن			
٣٢	خواردنەوەی کهولی ئەگەری بورانەوە(فیٚ) زیاد دەکات			
٣٣	زۆربەی بورانەوەکان(فیٚ) دەبێتەهۆی تێکچونی مێشك			
٣٤	پەستانی دەروونی لەوانەیە ببێتە هۆی هەندێك لە بورانەوەکان(فیٚ)			

بەشی ب

تکایە ئەم پرسیارانەی لای خوارەوە بخوێنەرەوە و نیشانەی (√) لەبەردەم ئەو پێوانەیە دابنیٚ کە گونجاو و ڕاستە بۆ تۆ:

		ڕۆژانە	کەمتر لە ڕۆژانە بەڵام زیاتر لە هەفتەی جارێك	کەمتر لە هەفتەی جارێك تا زیاتر لە مانگی جارێك	کەمتر لە مانگی جارێك تا زیاتر لە ساڵی جارێك	کەمتر لە ساڵی جارێك

١	چەند بە زووزوویی تووشی بورانەوە(فێ) دەبیت؟(تکایە یەك دانە هەڵبژێرە)					

(پیاچوونەوەی پێوانەی لیڤەرپوڵ بۆ قورسایی بورانەوە)

تکایە بە بیر کردنەوە لە چوار هەفتەی ڕابووردوو، ئەم بۆشایی یەی خوارەوە پڕ بکەرەوە بە ئاماژەکردن بۆ خراپترین بورانەوە(فێ) کانی کە بەسەر تۆدا هاتووە لەو ماوەیەدا:

٢ - لە ماوەی چوار هەفتەی ڕابووردوودا چەند جار تووشی بورانەوە(فێ) بوویت؟........................... بورانەوە

(تکایە سفر { ٠ } داخڵ بکە ئەگەر ئەزمونێك یان بورانەوەت نەبووە لە ماوەی چوار هەفتەی ڕابووردوودا. ئەگەر بە بیرت نایەت، تکایە بە نزیککردنەوە ئەو ژمارەیە بنووسە کە عادەتەن لە ڕۆژێکدا یان لەهەفتەیەکدا تووش دەبی.

		زۆر بەهێز بووە	بەهێز بووە	خاو بووە	زۆرخاو بووە
٣	پێم وایە کە بەهێزترین(توندترین) بورانەوە(فێ) کە تووشم بووەزۆربەی:				

		کەمتر لە یەك خولەك بێ هۆش دەبم	لە نێوان ١-٢ خولەك بێ هۆش دەبم	لە نێوان٣-٥ خولەك بێ هۆش دەبم	لە ٥ خولەك زیاتر بێ هۆش دەبم	هەرگیز لەهۆش خۆم ناچم/ بێ هۆش نابم
٤	زۆربەی کات کە لە هۆش خۆم دەچم بۆ ماوەی:					

		هەمیشە	ئاسایی(عادەتەن)	هەندێ جار	هەرگیز
٥	لە کاتی زۆربەی بورانەوە توند و سەختەکانم، بە لێوم دەکێشم، جموجوڵ یان بە شێوازێکی نائاسایی هەڵسوکەوت دەکەم				

		زۆر سەرلێ شێواو دەبم	بڕێکی باش سەرلێ شێواو دەبم	تۆزێك سەرلێ شێواو دەبم	هەست بە سەرلێ شێواوی ناکەم
٦	لەپاش زۆربەی بورانەوە توند و سەختەکانم:				

		کەمتر لە یەك خولەك	لە نێوان ١-٥ خولەك	لە نێوان ٦خولەك تا ١ کاتژمێر	لە نێوان ١ -٢ کاتژمێر	زیاترلە ٢ کاتژمێر	هەرگیز سەرلێ شێواو نەبووم
٧	لەپاش زۆربەی بورانەوە توند و سەختەکانم سەرلێ شێواوییەکەم ماوەی:						

		هەمیشە دەکەومە سەرزەوی	ئاسایی(عادەتەن) دەکەومە سەرزەوی	هەندێ جار دەکەومە سەرزەوی	هەرگیز ناکەومە سەر زەوی
٨	لە کاتی زۆربەی بورانەوە توند و سەختەکانم:				

		هەمیشە تووشی سەرئێشە دەبم	ئاسایی تووشی سەرئێشە دەبم	هەندێ جار تووشی سەرئێشە دەبم	هەگیز تووشی سەرئێشە نابم
٩	لە پاش زۆربەی بورانەوە توند و سەختەکانم:				

		هەمیشە خەواڵوو دەبم	ئاسایی خەواڵوو دەبم	هەندێ جار خەواڵوو دەبم	هەرگیز خەواڵوو نابم
١٠	لە پاش زۆربەی بورانەوە توند و سەختەکانم:				

		هەمیشە بۆم دەردەکەوێ کەخۆم تەڕکردووە	ئاسایی بۆم دەردەکەوێ کەخۆم تەڕکردووە	هەندێ جار بۆم دەردەکەوێ کەخۆم تەڕکردووە	هەرگیزخۆم تەڕنەکردووە
١١	لە پاش زۆربەی بورانەوە توند و سەختەکانم:				

		هەمیشە بۆم دەردەکەوێ کە زمانم گەستووە	ئاسایی بۆم دەردەکەوێ کە زمانم گەستووە	هەندێ جار بۆم دەردەکەوێ کە زمانم گەستووە	هەرگیز زمانم ناگەستم
١٢	لە پاش زۆربەی بورانەوە توند و سەختەکانم:				

		هەمیشە بۆم دەردەکەوێ کە خۆم بریندار کردووە	ئاسایی بۆم دەردەکەوێ کە خۆم بریندار کردووە	هەندێ جار بۆم دەردەکەوێ کە خۆم بریندار کردووە	هەرگیز خۆم بریندارناکردووە
١٣	لە پاش زۆربەی بورانەوە توند و سەختەکانم:				

		لە کەمتر لە ١ خولەك	لە نێوان ١ تا ٥ خولەك	لە نێوان٦خولەك تا ١ کاتژمێر	لە نێوان ١ تا ٢ کاتژمێر	زیاتر لە ٢ کاتژمێر
١٤	پاش زۆربەی بورانەوە سەختەکانم (سەرەڕایی گەستنی زمانم) ئەتوانم ئاسایی بگەڕێمەوە سەر ئەو کارەی دەیکەم :					

بەشی ج

تکایە ئەم دەستەواژانەی لای خوارەوە بخوێنەرەوە و نیشانەی √ لە ئەو پێوانەیە بدە کە ڕازی\ناڕازی بوونت بۆ دەستەواژەکە دەربخات:

	دەستەواژە	زۆر بە توندی ڕازیم	ڕازیم	نە ڕازیم و نە نا ڕازیم	ناڕازیم	زۆر نا ڕازیم
١	ڕەگەزخوازی(ڕەگەز جیایی)م بەرامبەر کراوە لەبەر ئەوەی نەخۆشی (پەرکەم) م هەیە					
٢	هەندێ جاروا هەست دەکەم کە بە ئاستێکی نزم قسە م لەگەڵ کراوە لەبەرئەوە ی نەخۆشی (پەرکەم) م هەیە					
٣	تووشبوونم بە نەخۆشی پەرکەم وای لێکردووم کە مرۆڤێکی تێگەیشتووتربم					
٤	هەست بە خراپی ناکەم لە بارەی					

	تووشبوونم به نەخۆشی پەرکەم					
٥	هەست به نیگەرانی دەکەم ئەگەر خەڵکی بزانن دەرمانی نەخۆشی پەرکەم دەخۆم					
٦	هەندێ کەس له تووشبووانی نەخۆشی پەرکەم مەترسیدارن					
٧	خەڵك تێگەیشتوون کاتێك دەزانن نەخۆشی پەرکەمم هەیه					
٨	له لایەن پۆلیسەوە ڕەگەزخوازی(ڕەگەز جیایی)م بەرامبەر کراوه لەبەر ئەوەی نەخۆشی (پەرکەم) م هەیه					
٩	لەلایەن خاوەن ئیشەوە ڕەگەزخوازی(ڕەگەز جیایی)م بەرامبەر کراوه لەبەر ئەوەی نەخۆشی (پەرکەم) م هەیه					
١٠	تووشبوونم به نەخۆشی پەرکەم زیاتر وای لێکردووم که خەڵکانی تر قبوڵ بکەم					
١١	زۆربەی کات هەست به تەنهایی دەکەم، لەبەر ئەوەی نەخۆشی (پەرکەم) م هەیه					
١٢	دەترسم لەوەی که کاردانەوەی خەڵك چۆن دەبێ که بزانن نەخۆشی (پەرکەم) م هەیه					
١٣	پێم وایه که فرسەتی زیاترم دەبوو له ژیانم دا ئەگەر تووشی پەرکەم نەبوومایه					
١٤	بەلامەوە ئاسایی یه ئەگەر خەڵکی دەوروبەر و دراوسێکانم بزانن که نەخۆشی (پەرکەم) م هەیه					

١٥	کاتێك داواکاری پێشکەش دەکەم بۆ کارێك، پێیان دەڵێم کە نەخۆشی (پەرکەم) م هەیە					
١٦	نیگەرانم(دەترسم) لەوەی بە خەڵکی بڵێم کە نەخۆشی پەرکەمم هەیە					
١٧	کاردانەوەی خەڵك بەرامبەر تووشبوونم بە نەخۆشی پەرکەم، هەر بۆخۆم هەڵدەگرم و نایدرکێنم					
١٨	توڕەم لە بەرامبەر کاردانەوەی خەڵك کە دەزانن نەخۆشی (پەرکەم) م هەیە					
١٩	تووشی هیچ کێشەیەك نەبووم لەلایەن خەڵکەوە لەبەرئەوەی کە نەخۆشی (پەرکەم) م هەیە					
٢٠	لەلایەن کەسانی شارەزای بواری تەندروستی ڕەگەزخوازی(ڕەگەز جیایی)م بەرامبەر کراوە لەبەر ئەوەی نەخۆشی (پەرکەم) م هەیە					
٢١	خەڵکی خۆیانم لێ لادەدەن لەبەر ئەوەی نەخۆشی (پەرکەم) م هەیە					
٢٢	خەڵکی بێ ڕێزیان بەرامبەرکردووم چونکە نەخۆشی (پەرکەم) م هەیە					
٢٣	تووشبوونم بە نەخۆشی پەرکەم وای لێکردووم کە مرۆڤێکی بەهێزتربم					
٢٤	هەست بە شەرمەزاری و شپرزەیی دەکەم چونکە نەخۆشی(پەرکەم) م هەیە					
٢٥	خۆم لادەدەم لەوەی بە خەڵك بڵێم کە نەخۆشی (پەرکەم) م هەیە					
٢٦	تووشبوونم بە نەخۆشی پەرکەم وام لێ دەکا کە بڵێم ژیان نارەوا و ناهەقە					

٢٧	وا هەست دەکەم کە پێویست دەکات نەخۆشی پەرکەمەکەم لە هاوڕێکانم بشارمەوە					
٢٨	قورسە بەلامەوە بە خەڵکی بڵێم کە نەخۆشی پەرکەمم لەگەڵە					

بەشی د

ئەم پرسیارانەی لای خوارەوە دەربارەی ئەوەیە کە چۆن پەرکەم کاری لە ژیانت کردووە، تکایە بازنە بەو ژمارەیەدا بهێنە کە چوونیەکە لەگەڵ ڕاوبۆچوونی تۆدا:

١)چۆن نەخۆشی پەرکەم کار لە ژیانت دەکات؟

هیچ کاریگەرییەکی

بەسەختیکارلە ژیانم دەکا

١٠ ٩ ٨ ٧ ٦ ٥ ٤ ٣ ٢ ١ ٠

٢)بە ڕای تۆ نەخۆشی پەرکەمەکەت تاکەی بەردەوام دەبێت؟

بۆ هەتا ماوەیەکی زۆرکەم

هەتایە

١٠ ٩ ٨ ٧ ٦ ٥ ٤ ٣ ٢ ١ ٠

٣)هەست دەکەی چەندێك دەتوانی کۆنترۆڵی نەخۆشی پەرکەمەکەت بکەی؟

کۆنترۆڵێکی بەتەواوی هیچ کۆنترۆڵێك

لەڕادەبەدەر

١٠ ٩ ٨ ٧ ٦ ٥ ٤ ٣ ٢ ١ ٠

٤)پێت وایە چەندێك چارەسەرکردن بتوانێ یارمەتی نەخۆشی پەرکەمەکەت بدات؟

لە هیچ

ڕادەبەدەر یارمەتیدەرە

١٠ ٩ ٨ ٧ ٦ ٥ ٤ ٣ ٢ ١ ٠

٥)چەندێك هەست بە نیشانەکانی نەخۆشی یەکەت دەکەیت؟

هیچ نیشانەیەك

زۆر لە نیشانە سەختەکان

١٠ ٩ ٨ ٧ ٦ ٥ ٤ ٣ ٢ ١ ٠

٦)چەند نیگەرانی لەبارەی نەخۆشی یەکەتەوە؟

هیچ نیگەران نیم

لە ڕادەبەدەر   نیگەرانم

١٠ ٩ ٨ ٧ ٦ ٥ ٤ ٣ ٢ ١ ٠

٧)هەست دەکەی چەندە تێدەگەی لە نەخۆشی پەرکەمەکەت؟

هیچ تێ ناگەم

زۆر بە ڕوونی تێ دەگەم

١٠ ٩ ٨ ٧ ٦ ٥ ٤ ٣ ٢ ١ ٠

٨)ئایا نەخۆشی پەرکەمەکەت چەندە کاری لە سۆزداریت کردووە؟

لە   هیچ کاری لە سۆزداریم نەکردووە
ڕادەبەدەر کاری لە سۆزداریم نەکردووە

١٠ ٩ ٨ ٧ ٦ ٥ ٤ ٣ ٢ ١ ٠

٩)تکایە لیستی ئەو سێ هۆکارە گرنگە بە ڕیز و بە پێی پلەی گرنگیان بنووسە کە بە باوەڕی تۆ بوونەتە هۆی تووشبوونت بە پەرکەم:-

١)-

____

____

٢)____

____

٣)____

____

بەشی هـ

لە خوارەوە لیستی ئەو شێوازانەیە کە لەوانەیە بەو جۆرە هەست یان هەڵسوکەوتت کردووە. تکایە پێم بڵێ کە چەند زوو زوو بەو شێوەیە هەستت کردووە لە هەفتەی ڕابووردوودا.

	لە ماوەی هەفتەی ڕابووردوودا	دەگمەن یان لە هیچ کاتێکدا(کەمتر لە ١ ڕۆژ)	هەندێك یان بۆ کاتێکی کەم(١-٢ ڕۆژ)	ناوبەناو یان کاتێکی مامناوەند(٣-٤ ڕۆژ)	زۆربەی یان هەموو کاتێك(٥-٧ ڕۆژ)
١	نیگەران بووم بە چەند شتێك کە بە ئاسایی نیگەرانم ناکەن				

٢	حەزی خواردنم نەمابوو، ئارەزووی خواردنم خراپ بوو				
٣	هەستم کرد کە بێ تاقەتییەکەم ناڕوات تەنانەت بە یارمەتی خێزان یان هاوڕێکانیشم				
٤	هەستم کرد کە باشم بەقەت خەڵکانی تر				
٥	هەستم کرد کە گرفتم هەیە لەوەی بیروهۆش بدەمە ئەو کارەی کەدەیکەم				
٦	هەستم بە کأبة کرد				
٧	هەستم کرد کە هەرچییەکم کرد ڕەنجی ویست				
٨	هەستم بە گەشبینی کرد لە بارەی دواڕۆژەوە				
٩	وابیرم کردەوە کە ژیانم شکستی هێناوە				
١٠	هەستم بە ترس کرد				
١١	خەولێکەوتنم بێ ئارام بوو				
١٢	دڵ خۆش بووم				
١٣	کەمتر لە ئاسایی قسەم کرد				
١٤	هەستم بە تەنهایی کرد				
١٥	خەڵکی (unfriendly)یارمەتیدەرنەبوون				
١٦	خۆشیم لە ژیان بینی				
١٧	ناوبەناو گریانم دەهات				
١٨	هەستم بە خەمباری کرد				
١٩	هەستم کرد خەڵکی ڕقیان لێمە				

٢٠	نەمدەتوانی دەست بە هیچ بکەم				

بەشی و

ئەم پرسیارانەی لای خوارەوە لەبارەی ئەوەیە کە پەرکەم چۆن کاری لە ژیانت کردووە.پرسیارەکان لە بارەی چۆن هەست کردنت و جۆری ئەو گیروگرفتانەیە کە دووچارت هاتوون لە ماوەی ٤ هەفتەی ڕابووردوودا. بۆ هەر پرسیارێك، تکایە ئەو وەڵامە هەڵبژێرە کە نزیکترینە لەوەی کە هەستت چۆن بووە.

(لە هەر خەتێك، بازنە بە یەك ژمارەدا بێنە)

	چەند جار لە ماوەی ٤ هەفتەی ڕابووردوودا	هەموو کات	زۆربەی کات	بڕێکی باشی کات	هەندێك کات	تۆزێك کات	هیچ کات
١	ئایا ووزەیەکی زۆرت هەبووە؟	١	٢	٣	٤	٥	٦
٢	هەستت بە بێ تاقەتی و دڵتەنگی کرد؟	١	٢	٣	٤	٥	٦

		کاریگەری گەورە	زۆر	هەندێك	کەمێك	هیچ
٣	لە ماوەی ٤ هەفتەی ڕابووردوودا پەرکەم یان دەرمانی پەرکەم چەند کاریگەری هەبووە لەسەر لێخوڕینت(یان شێوەیەکی تری هاتوچۆت)	١	٢	٣	٤	٥

	لە ماوەی ٤ هەفتەی ڕابووردوودا	هیچ بێزارم ناکات	کەمێك	هەندێك	زۆر	زۆر زۆر بێزارم دەکات
٤	چەندە سنورداری ئیش وکار بێزارت دەکات؟	١	٢	٣	٤	٥
٥	چەند سنورداری کۆمەڵایەتی بێزارت دەکات؟	١	٢	٣	٤	٥
٦	چەندە زەحمەتی لەبیرهاتنەوە بێزارت دەکات؟	١	٢	٣	٤	٥

٧	چەندە کاریگەری جەستەیی کە بەهۆی دەرمانی دژە پەرکەمەوە پەیدا بووە، بێزارت دەکات؟	١	٢	٣	٤	٥
٨	چەندە کاریگەری دەروونی کە بەهۆی دەرمانی دژە پەرکەمەوە پەیدا بووە، بێزارت دەکات؟	١	٢	٣	٤	٥

		زۆر دەترسم	هەندێك دەترسم	زۆر ترسم نی یە	هیچ ترسم نی یە
٩	چەندە دەترسی کە لە ماوەی ٤ هەفتەی داهاتوودا ببورێیتەوە(فێ بتگرێ)؟	١	٢	٣	٤

١٠ ـ لە ماوەی ٤ هەفتەی ڕابووردوودا، ئاستی ژیانت چۆن بووە(یاخود چۆن بەڕێوەچووە)؟

زۆر باش بووە، قەت وا باش نەبووە	باش بووە	باش و خراپ وەك یەك بووە	خراپ بووە	زۆر خراپ بووە، قەت وا خراپ نەبووە
١	٢	٣	٤	٥

بە پێداچوونەوەی هەموو ئەو پرسیارانەی پێشوو کە وەڵامت دانەوە، بە ڕەچاوکردنی گشت کاریگەری ئەو گیروگرفتانەی کاریان لە چۆنێتی ژیانت کردووە لە ماوەی ٤ هەفتەی ڕابووردوودا (بازنە بە یەك ژمارەدا بێنە)

		هیچ	هەندێك	بڕێکی مام ناوەند	زۆر	زۆر زۆر
١١	بە گشتی باری نەخۆشی پەرکەم و پەیوەندی بە ئاستی ژیان و گوزەرانتەوە، چەندە نیگەرانی کردووی؟	١	٢	٣	٤	٥

بە ڕەچاوکردنی هەموو ئەو پرسیارانەی کە وەڵامت دانەوە، تکایە دەستنیشانی ئەو بوارانە بکە کە پەیوەندی بە نەخۆشی پەرکەمەکەتەوە هەیە وگرنگیەکی زۆری هەیە بەلای تۆوە بۆ ئێستا

١٢ ـ ئەم دەستەواژانەی خوارەوە ڕێك بخە لە ١ تا ٧ بە جۆرێك کە " ١ " هاوتای گرنگترین بابەت و " ٧ " کەمترین گرنگی هەبێت. تکایە هەر ژمارەیەك یەك جار بەکاربهێنە.

☐ أ. ووزه و تاقەت (هیلاکی)

☐ ب. سۆز (مەزاج)

☐ ج. چالاکی ڕۆژانە(کار،لێخوڕین،کۆمەڵایەتی و چالاکیەکانی تر)

☐ د. فرمانی دەروونی(بیرکردنەوە، ووردبوونەوە[هۆش پێدان]، بیر)

☐ هـ . کاریگەری دەرمان(جەستەیی، دەروونی)

☐ و. دڵەڕاوکێی بورانەوە[فێ](کاریگەری بورانەوەکان)

☐ ز. جۆرێتی(چۆنێتی) ژیان بە گشتی

زۆر سوپاس بۆ بەشداریت لەم توێژینەوەیەدا، تکایە هەر تێبینی یەکت هەیە لەسەر پرسیارەکانی کە لێت کرا لەبارەی خۆت یان نەخۆشی پەرکەم لە خوارەوە بینووسیت

من ئارەزوومەندم کە هەندێ پرسیاری زیاترت لێ بکەم لە ١٠ -١٢ مانگی تردا، تکایە هەڵیبژێرە کە پێتخۆشە پەیوەندیت پێوە بکەم بۆ ئەو مەبەستە: ☐ بەڵێ ☐ نەخێر

ئەگەر بەڵێ ت هەڵبژارد، تکایە لە خوارەوە زانیاری پەیوەندیکردن دابین بکە:

ناو:

ژمارەی تەلەفۆن:

ئیمەیڵ:

10.11. Consent Form – People with Epilepsy – UK – Study 2

Brunel
UNIVERSITY
WEST LONDON

Knowledge and quality of life of people with epilepsy in the UK

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 ‘‘Knowledge and quality of life of people with epilepsy in the UK’’ to be conducted at Brunel University, with ‘‘Nashmel Sargalo’’ as principal investigator. The broad goal of this research program is to explore how much you know about epilepsy and how epilepsy may have affected you and your life. Specifically, I have been told that I will be asked to complete a questionnaire. This session should take no longer than 30 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 a better understanding, care, and education of epilepsy for those living with epilepsy and for doctors and nurses who help care for people with epilepsy in general – not any particular individual’s personal knowledge and views 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 Nashmel Sargalo at nashmel.sargalo@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 or Dr Tara Marshall at 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 Name 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 Name Date

10.12. Debriefing Form – UK – Study 2

Knowledge and quality of life of people with epilepsy in the UK

The aim of this study is to explore knowledge and the quality of life of people with epilepsy.

It is documented culture plays a role in peoples' understanding of epilepsy and this may affect how it is dealt with. Sufferers of epilepsy from different cultures deal with their illness in different ways.

If you would like to have more information about this area of research please refer to the following articles:

1) ‘‘Quantitative Assessment of seizure Severity for Clinical Trials: A review of Approaches to Seizure Components’’ by Cramer and French (2001), *Epilepsia*, **42**(1):119-129.

2) ‘‘Cross-cultural Differences in Levels of Knowledge about Epilepsy’’ by Doughty et al (2003), Epilepsia, **44**(1): 115-123.

3) ‘‘Social and Family characteristics of Hispanic with epilepsy’’ by Chong et al (2011), *Seizure*, **21**(2012) 12-16

4) For more information on epilepsy please see the link below:

http://www.epilepsy.org.uk/

Thank you again for taking part in this important study.

10.13. Consent Form Kurdistan – Study 2

زانیاری و چۆنێتی(جۆرێتی) ژیانی کەسانی تووش بوو بە پەرکەم لە کوردستان/باکوری عیراق

بەشی دەروونناسی لە زانکۆی برونێڵ داواکارە لە هەموو ئەوکەسانەی کە بەشداری دەکەن لە لێکۆڵینەوەی دەروونناسی دا،ڕێپێدان و ڕازیبوونی خۆیان دەربڕن بۆ ئەنجامدانی ئەم کارە.تکایە ئەم نوسراوەی خوارەوە بخوێنەرەوە و ئیمزای بکە ئەگەر ڕازییت بە ناوەڕۆکەکەی.

من بە ئارەزووی خۆم و خۆبەخشانە ڕازیم کە بەشداری بکەم لەم پڕۆژەی لێکۆڵینەوەیە بە ناونیشانی(زانیاری و چۆنێتی(جۆرێتی) ژیانی کەسانی تووش بوو بە پەرکەم لە کوردستان/باکوری عیراق) کە لە لایەن زانکۆی برونێڵ ئەنجام دەدرێ بە سەرپەرشتی " نەشمیل سەرگەڵویی" وەك بەرپرسی لێکۆڵەرەوە.ئامانجی بەرفراوانی ئەم پرۆگرامی لێکۆڵینەوەیە بۆ دۆزینەوەی ئەوەیە کە بزانرێت چەند لەبارەی پەرکەم ەوە دەزانیت و چۆن پەرکەم کاریگەری لەخۆت و ژیانت کردووە یان نا. بە تایبەتیش پێم ووتراوە کە کە داوام لێ دەکرێ کە ڕاپرسییەك پڕبکەمەوە. ئەم بەشە لە ٣٠ دەقیقە زیاتر ناخایەنێت بۆ تەواوکردن.

پێم ڕاگەیەنراوە کە وەڵامەکانم بە تەواوەتی بە شێوەیەکی نهێنی دەمێنێتەوە. ئەوەش دەزانم کە لە هەرکاتێکی پڕکردنەوەی ئەم فۆرمەدا من ئازادم کە بڵێم ناتوانم یان نامەوێت بەردەوام بم، من ئازادم وازبێنم بێ هیچ دەرئەنجامێکی سەلبی و خراپ. بەشداری کردنیشم لەم لێکۆڵینەوەیەدا بە تەواوەتی خۆبەخشانەیە و لەوانەیە لەهەرکاتێکدا پاشەکشێ بکەم. پاشەکشەکردنم نابێتەهۆی هیچ سزایەکی ئەکادیمی یان هەرجۆرێکی تر. ناوم پەیوەست ناکرێ بە بابەتەکانی لێکۆڵینەوەکە، چونکە لێکۆڵەرەوەکە دەیەوێت کە باشترتێگەیشتن، بایەخدان وڕۆشنبیری لەسەر پەرکەم بۆ کەسانی تووشبوو بە پەرکەم ودکتۆر و پەرستیار کە یارمەتی و بایەخ دەدەن بە پەرکەم بەرجەستە بکات بەگشتی- نەك زانیاری شخصی وبۆچوونی تاکەکەسێك بە تایبەتی. ڕێگام پێدراوە کە پرسیاربکەم لە بارەی شێوازوڕێگەی لێکۆڵینەوەکە و وەك پێویست وەڵامم دراوەتەوە. پێم ووتراوە کەهەر پرسیارێکم هەیە بە گشتی لە بارەی ئەم پرۆژەیە یان کێشەیەکی ڕەوشتی کە پەیوەندی بە پرۆژەکەوە هەیە، دەتوانم ئازادانە پەیوەندی بکەم بە نەشمیل سەرگەڵویی لە ڕێگای
nashmel.sargalo@brunel.ac.uk . ئەگەر هەر گلەیی یان ڕەخنەیەکم هەبێ لەبارەی شێوازی بەڕێوەچوونی
لێکۆڵینەوەکە یان بە ئەنجام گەیاندنی دەتوانم پەیوەندی بکەم بە یەکێك لە بەرپرسانی لێکۆڵینەوەی دەروونناسی
لە ڕێگای Tara Marshall یان دکتۆر taeko.wydell@brunel.ac.uk لە ڕێگای Taeko Wydell پرۆفیسۆر
tara.marshall@brunel.ac.uk .

ئەم ڕێ پێدانی بەشداربوونەی سەرەوەم خوێندەوە و تێیگەیشتم. ئیمزاکەم ئیمزاکەم نابێتە هۆی دەستبەرداربوونم لە مافە یاسایی یەکانم. دواتریش دەتوانم کە کۆپییەکی ئەم فۆرمە وەك تۆمارێك لای خۆم هەڵگرم.

....	....	....
بەروار	ناوی بەشداربوو	ئیمزای بەشداربوو

بە دوورودرێژی شێوازی لێکۆڵینەوەکەم شی کردەوە و پێناسە کرد بۆ ئەم بەشداربووەی لای سەرەوە و ئەویش ڕازیی بوو کە بەشداری بکات. دواتریش دەتوانم کە کۆپییەك لەم نوسراوی ڕێ پێدانە وەك تۆمارێك لای خۆم هەڵگرم.

....

ئیمزای سەرپەرشتیاری لێکۆڵەرەوە ناوی لێکۆڵەرەوە بەروار

10.14. Debriefing Form Kurdistan– Study 2

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زانیاری و چۆنێتی(جۆرێتی) ژیانی کەسانی تووش بوو بە پەرکەم لە کوردستان/باکوری عیراق

ئامانجی ئەم توێژینەوەیە بۆ گەڕانە بەدوای زانیاری وچۆنێتی(جۆرێتی) ژیانی ئەو کەسانەیە کە نەخۆشی پەرکەم یان هەیە.

بەڵگەنامەکان دەیسەلمێنن کە نەریت ڕۆڵێکی کاریگەری هەیە لەسەر نەخۆشی پەرکەم و لەوانەیە ئەمەش کاربکات لە شێوەی مامەڵەکردن لەگەڵیدا.

ئەگەر زانیاری زیاترت ویست لەسەر لێکۆڵینەوەکان لەم بوارەدا بگەڕێرەوە بۆ ئەم بابەتانەی لای خوارەوە:

1) ‘‘Quantitative Assessment of seizure Severity for Clinical Trials: A review of Approaches to Seizure Components’’ by Cramer and French (2001), *Epilepsia*, **42**(1):119-129.

2) ‘‘Cross-cultural Differences in Levels of Knowledge about Epilepsy’’ by Doughty et al (2003), Epilepsia, **44**(1): 115-123.

3) ‘‘Social and Family characteristics of Hispanic with epilepsy’’ by Chong et al (2011), *Seizure*, **21**(2012) 12-16
4) بۆ زانیاری زیاتر لەسەر پەرکەم(فێ) بە زمانی کوردی ئەم لینکەی خوارەوە بخوێنەرەوە:

http://www.epilepsy.org.uk/sites/epilepsy/files/epilepsyaction_newtoepilepsy_kurdish.pdf

دووبارە زۆر سوپاس بۆ بەشداربوونت لەم توێژینەوە گرنگەدا

10.15. Questionnaire People without Epilepsy- UK - Study 3

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Hello, thank you for agreeing to take part in this questionnaire. The following questions are about you, please answer as truthfully as you can. There are no right or wrong answer, I am only interested in your views.

Age: Gender (please tick one): Male ☐ Female ☐

Marital Status (please tick one): Single ☐ Married ☐ Divorced ☐ Widowed ☐
Occupation:
Highest Educational Qualification:
Country/Town of Birth:
Country/Town of Residence (if different from above):
Time at Place of Residence:

SECTION A

Please read the following questions carefully and answer what’s true for you.

1) Do you know or have you ever known anyone who had epilepsy? Yes ☐ No ☐
2) Would you object to a person with epilepsy marrying a close relative of yours (brothers, sisters, or child)?
Yes ☐ No ☐
3) Would you object to having any of your (eventual) children associate with persons who sometimes had epileptic seizures in school or in a playground? Yes ☐ No ☐
4) Do you think that, in general, persons with epilepsy should be employed at the same jobs as other people? Yes ☐ No ☐

The following statements contain information about epilepsy, please decide whether you think the statement is TRUE or FALSE and tick accordingly

	Statements	TRUE	FALSE
1	Epilepsy is always caused by brain damage		
2	Epilepsy is not infectious		
3	Epilepsy is a symptom of mental illness		
4	All people with epilepsy have similar symptoms		
5	Almost anyone can have a seizure given the appropriate circumstances		
6	An EEG can be used to help diagnose epilepsy		
7	If an EEG is abnormal, this is a definite sign of epilepsy		

8	An EEG is designed to detect electrical activity from the brain		
9	All people with epilepsy lose consciousness during seizures		
10	An epileptic seizure can be described as a temporary lack of oxygen to the brain		
11	Some seizures may last for a matter of seconds and not be noticed by others		
12	All seizures affect both sides of the brain		
13	Certain forms of brain damage always cause epilepsy		
14	A normal EEG means that you do not have epilepsy		
15	For most people, doctors can effectively treat epilepsy with drugs		
16	All those who start drugs for their epilepsy have to take them for life		
17	Increasing the dose of antiepileptic drugs increases the chances of side effects		
18	An epileptic seizure can be described as an abnormality in the function of nerve cells in the brain		
19	For antiepileptic drugs to be successful, they must be taken regularly		
20	If you forget to take antiepileptic drug for a day, it is usually OK to take two doses together		
21	Some people get a warning or feeling shortly before a seizure		
22	Blood samples can be used to measure the concentrations of antiepileptic drugs in the system		
23	People taking a combination of antiepileptic drugs are more likely to have side effects than those taking only one		
24	Most people’s seizures are well controlled soon after starting regular drug treatment		
25	It is always helpful to take extra doses of antiepileptic drugs when not feeling well		
26	If seizures stop with antiepileptic drugs, this means your epilepsy has been cured		
27	Few people with a diagnosis of epilepsy are taking antiepileptic drugs		
28	Some people have been taught to control their seizures by psychological methods		
29	There is no need to continue taking antiepileptic drugs if your seizures stop		
30	Brain surgery is still used as a method of preventing seizures		
31	Most mothers taking antiepileptic drugs are able to breastfeed		
32	Too much alcohol may make seizures more likely		
33	Most seizures result in brain damage		
34	Stress may cause some seizures		

SECTION B

After reading each of the following questions, please indicate your thoughts on the following scale to show your opinions about epilepsy

Please be as honest as possible in your answers.

	Questions	Not at all	A little	A lot	Totally
1	Do you think people with epilepsy feel able to control their own epilepsy?				
2	What do (would) you feel when you see (if you saw) an epileptic seizure? a) Shock				
	b) Fear				
	c) Sadness				
	d) Pity				
3	Which difficulties do you think people with epilepsy have in their lives? a) Family				
	b) Work				
	c) School				
	d) Social relationships				
	e) Sexual				
	f) Emotional				
	g) Prejudice				
4	How do you think people with epilepsy feel? a) Worried				
	b) Dependent				
	c) Incapable				
	d) Fearful				
	e) Ashamed				
	f) Sad				
	g) No different				
5	In your opinion, in which situation does prejudice against epilepsy occur: a) Social relationships				
	b) Marriage				
	c) Work				
	d) School				
	e) Family				

Thank you for taking the time to complete this questionnaire, please feel free to make any comments about the questions or epilepsy below.

10.16. Questionnaire People without Epilepsy – Kurdistan – Study 3

سڵاو، سوپاس کە ڕازی بوویت کە بەشداری بکەیت لەم ڕاپرسی یەدا. ئەم پرسیارانەی لای خوارەوە لەبارەی تۆوەیە، تکایە چەندی توانیت بە ڕاستگۆیی وەڵامیان بدەرەوە. هیچ وەڵامێکی غەڵەت یان ڕاست ی تێدا نی یە، من تەنها ئارەزوومەندم کە ڕاو بۆچوونەکانی تۆ بزانم.

تەمەن: رەگەز: □ نێر □مێ

باری خێزانی(هاوسەرگیری): □ تەنیا(زگوردی) □ هاوسەرگیر(خێزاندار) □ جیابووەوە □ بێوەژن

پیشە:

بەرزترین پلەی خوێندن:

وولات/شاری لە دایك بوون:

وولات/شاری نیشتەجێ بوون(ئەگەرجیاوازە لەگەڵ سەرەوە):

ماوەی نیشتەجێ بوونت لەم شوێنە:

ئایا نەخۆشی پەرکەم ت تیا دیاری کراوە؟ □ بەڵێ □ نەخێر

بەشی أ

تکایە ئەم پرسیارانەی لای خوارەوە بە ووردی بخوێنەرەوە و وەڵامێك کە بۆ تۆ گونجاو و ڕاستە هەڵبیژێرە:

١-ئایا ئەزانیت یان کەسێکت ناسیوە کە نەخۆشی پەرکەمی هەبێت؟ □ بەڵێ □ نەخێر

٢-ئایا نارەزایی دەردەبڕیت ئەگەر کەسێکی تووشبوو بە پەرکەم داوای هاوسەرگیری بکات لەگەڵ یەکێك لە خزم و کەسە نزیکەکانی تۆ وەك(براکانت،خوشکەکانت یان منداڵەکانت)؟ □ بەڵێ □ نەخێر

٣- ئایا نارەزایی دەردەبڕیت ئەگەر منداڵەکانی خۆت تێکەڵی و هاوڕێی کەسانێك بکەن کە هەندێ جار تووشی بورانەوە و فێ دەبن لە قوتابخانە یان شوێنی یاری کردن؟ □ بەڵێ □ نەخێر

٤-بە گشتی، پێت وایە کەدەکرێت خەڵکانی تووشبوو بە پەرکەم هەمان هەلی ئیش وکارکردنیان پێ بدرێ وەك خەڵکی تر؟ □ بەڵێ □ نەخێر

ناوەڕۆکی ئەم دەستەواژانەی لای خوارەوە بریتی یە لە زانیاری دەربارەی پەرکەم، تکایە بڕیار بدە کە کام دەستەواژەیە ڕاستە یان هەڵەیە و نیشانەی بکە:

	دەستەواژەکان	ڕاستە	هەڵەیە
١	پەرکەم هەمیشە بەهۆی تێکچونی مێشکەوە ڕوودەدات		
٢	پەرکەم نەخۆشی یەکی درم نی یە(ناگوێزرێتەوە لە یەکێك بۆ یەکێکی تر)		

٣	پەرکەم نیشانەیەکە بۆ بوونی نەخۆشی دەروونی(مێشکی)		
٤	هەموو ئەو کەسانەی پەرکەمیان هەیە هەمان نیشانەی نەخۆشی یەکەیان هەیە		
٥	نزیکەی هەموو کەسێك ڕێی تێدەچێ ببورێتەوە ئەگەر بارودۆخی گونجاوی بۆ هەڵبکەوێ		
٦	* بەکاربهێنرێت بۆ دیاری کردن و دۆزینەوەی نەخۆشی پەرکەم EEGدەتوانرێت		
٧	نائاسایی بێت، بەدڵنیایی ئەوە نیشانەکی نەخۆشی پەرکەمە EEGئەگەر دەرئەنجامی		
٨	دروستکراوە تاوەکو چالاکی و جموجوڵی کارەبایی لە مێشکەوە بپشکنێت EEGئامێری		
٩	هەموو ئەو کەسانەی کە نەخۆشی پەرکەمیان هەیە لەکاتی بورانەوە(فێ)دا بێ هۆش دەبن		
١٠	بورانەوە(فێ) بەوە پێناسە دەکرێت کە بریتی یە لە کەم چوونی ئۆکسجین بۆ مێشك بە شێوەیەکی کاتی		
١١	هەندێ بورانەوە ماوەی چەند چرکەیەك دەخایەنێ و تێبینی ناکرێ لەلایەن خەڵکی ترەوە		
١٢	هەموو بورانەوەیەك کارلەهەردوو بەشی مێشك دەکات		
١٣	هەندێ شێوازی تێکچوونی مێشك هەمیشە دەبێتە هۆی پەرکەم		
١٤	ئاسایی بێت، مانای وایە نەخۆشی پەرکەمت نی یە EEGئەگەر دەرئەنجامی		
١٥	بۆ زۆربەی خەڵك، دکتۆر دەتوانێ کاریگەرانە چارەسەری پەرکەم بکات بە دەرمان		
١٦	هەموو ئەو کەسانەی کە دەرمان بەکاردەهێنن بۆ پەرکەم دەبێ بۆ هەتا هەتایە بیخۆن		
١٧	زیادکردنی بڕی دەرمانی دژەپەرکەم ئەگەری کاریگەری(زیانی) لاوەکی زیاد دەکات		
١٨	دەتوانرێ پێناسەی بورانەوە(فێ)بکرێ بەوەی کە بارێکی نائاسایی یە لە فەرمانی خانەکانی دەمار لە مێشکدا		
١٩	بۆ دەرئەنجامی باش و سەرکەوتوویی دەرمانی دژەپەرکەم،دەبێ بەردەوام بخورێت		
٢٠	ئەگەر بۆ ڕۆژێك لەبیرت بچێ دەرمانی پەرکەم بخۆیت، ئاسایی یە کە دواتر دوو بڕ بخورێت		
٢١	هەندێك کەس جۆرێك لە ئاگادارکردنەوە یان هەستێکیان دەبێ پێش بورانەوە(فێ)		
٢٢	دەتوانرێت خوێن وەك پێوانەیەك بەکاربهێنرێت بۆ دیاریکردنی خەستی دەرمانی پەرکەم لە لەشدا		
٢٣	ئەو کەسانەی دوو جۆر دەرمانی پەرکەم بەکاردێنن، زیاتر بۆی هەیە کاریگەری(زیانی) لاوەکی یان لەسەربێت وەك لەو کەسانەی یەك جۆر بەکاردێنن		

٢٤	بورانەوەی زۆربەی خەڵکانی تووشبوو بە پەرکەم زیاترکۆنترۆڵ دەکرێ یەکسەر دوای چارەسەری بەردەوام بە دەرمان		
٢٥	هەمیشە یارمەتیدەرترە ئەگەر بڕی زیاتری دەرمانی دژە پەرکەم بخورێ کاتێك هەست بە خراپی دەکەیت		
٢٦	ئەگەر بورانەوە(فێ)کانت بوەستێ پاش بەکارهێنانی دەرمان، مانای وایە پەرکەمەکەت چارەسەربووە		
٢٧	خەڵکێکی کەمی تووشبوو بە پەرکەم، دەرمانی چارەسەری دژە پەرکەم بەکاردێنێ، کاتێك دەستنیشانی نەخۆشیەکەی دەکرێت		
٢٨	هەندێك کەس وا فێرکراون کە کۆنترۆڵی بورانەوەکانیان بکەن لەڕێگای ڕێگەچارەی دەروونی یەوە		
٢٩	پێویست ناکات بەردەوام بیت لە خواردنی دەرمانی پەرکەم ئەگەر بورانەوەکانت وەستا		
٣٠	نەشتەرگەری مێشك وەك ڕێگاچارەیەك بەکاردێت بۆ ڕێگرتن لە بورانەوەکان		
٣١	زۆربەی ئەو دایکانەی لەسەر دەرمانی پەرکەمن، دەتوانن شیربدەن		
٣٢	خواردنەوەی کهولی ئەگەری بورانەوە(فێ) زیاد دەکات		
٣٣	زۆربەی بورانەوەکان(فێ) دەبێتەهۆی تێکچونی مێشك		
٣٤	پەستانی دەروونی لەوانەیە ببێتە هۆی هەندێك لە بورانەوەکان(فێ)		

بەشی ب

پاش خوێندنەوەی هەریەك لەم پرسیارانەی لای خوارەوە، تکایە ڕاوبۆچوونی خۆت دەستنیشان بکە لەسەر ئەم پێوانەیەی لای خوارەوە بۆ ئەوەی ڕای خۆت نیشان بدەی لەسەر نەخۆشی پەرکەم:

تکایە چەندی ئەتوانی ڕاستگۆیانە وەڵام بدەرەوە

	پرسیارەکان	هەرگیز نا	تۆزێك	زۆر	بە تەواوی
١	ئایا پێت وایە کە خەڵکی تووشبوو بە پەرکەم هەستکەن بتوانن کۆنترۆڵی پەرکەمەکەیان بکەن؟				
٢	هەست بەچی دەکەیت ئەگەر یەکێك ببینی تووشی بورانەوە(فێ) ببێت أ- واق ووڕمان(خورپە)				
	ب- ترس				

	ت- خەمباری				
	ث- بەزەیی				
٣	بە ڕای تۆ کەسانی تووشبوو بە پەرکەم چ گرانی و زەحمەتی یەکیان هەیە لە ژیانیاندا؟ أ- خێزانی				
	ب- ئیش و کار				
	ت- قوتابخانە				
	ث- پەیوەندی کۆمەڵایەتی				
	ج- جنسی				
	ح- سۆزداری				
	خ- ڕەگەزخوازی(کینەی ڕەگەز)				
٤	بە ڕای تۆ کەسانی تووشبوو بە پەرکەم هەست بە چی دەکەن؟ أ- شپرزەیی				
	ب- نا سەربەخۆیی				
	ت- بێ توانایی				
	ث- ترسنۆکیی				
	ج- شەرمەزاری				
	ح- خەمباری				
	خ- هیچ گۆڕانێك				
٥	بەڕای تۆلەچ بارودۆخێکدا ڕەگەزخوازی(کینە و ڕق) دژی تووشبووانی پەرکەم ڕوودەدات: أ- پەیوەندیە کۆمەڵایەتیەکان				
	ب- هاوسەرگیری				
	ت- ئیش (کار)				
	ث- قوتابخانە				
	ج- خێزانی				

سوپاس بۆ پڕکردنەوەی ئەم ڕاپرسی یە، تکایە ئازادبە ئەگەر هەر تێبینی یەکت هەیە لەسەر پرسیارەکان و نەخۆشی پەرکەم لەخوارەوە بینوسە

10.17. Consent Form – People without Epilepsy – UK – Study 3

Knowledge and view of Epilepsy among people in the UK

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 ‘‘Knowledge and view of Epilepsy among people in the UK’’ to be conducted at Brunel University, with ‘‘Nashmel Sargalo’’ as principal investigator. The broad goal of this research program is to explore how much you know about epilepsy and your opinions of people with epilepsy. Specifically, I have been told that I will be asked to complete a questionnaire. This session should take no longer than 10 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 understanding of how epilepsy is viewed by people in the UK in general – not any particular individual’s personal knowledge and views 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 Nashmel Sargalo at nashmel.sargalo@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 or Dr Tara Marshall at 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 Name 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 Name Date

10.18. Debriefing Form – People without Epilepsy – UK – Study 3

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Knowledge and view of Epilepsy among people in the UK

The aim of this study is to explore people's views and attitudes to those with epilepsy.

It is well documented that people who have better knowledge of epilepsy are more accepting of people who have epilepsy.

If you would like to have more information about this area of research please refer to the following articles:

1) ‘‘An epilepsy Questionnaire study of Knowledge and Attitudes in Canadian College Students’’ by Young et al (2002), *Epilepsia*, **43**(6): 652-658.

2) ‘‘Cross-cultural Differences in Levels of Knowledge about Epilepsy’’ by Doughty et al (2003), Epilepsia, **44**(1): 115-123.

3) For more information on epilepsy please see the link below:

   http://www.epilepsy.org.uk/

Thank you again for taking part in this important study.

10.19. Consent Form – People without Epilepsy - Kurdish – Study 3

زانیاری و بۆچوون لە سەر پەرکەم(فێ) لە ناو خەڵکانی کورد لە کوردستان/باکوری عیراق

بەشی دەروونناسی لە زانکۆی برونێڵ داواکارە لە هەموو ئەوکەسانەی کە بەشداری دەکەن لە لێکۆڵینەوەی دەروونناسی دا،ڕێپێدان و ڕازیبوونی خۆیان دەربڕن بۆ ئەنجامدانی ئەم کارە.تکایە ئەم نوسراوەی خوارەوە بخوێنەرەوە و ئیمزای بکە ئەگەر ڕازییت بە ناوەڕۆکەکەی.

من بە ئارەزووی خۆم و خۆبەخشانە ڕازیم کە بەشداری بکەم لەم پرۆژەی لێکۆڵینەوەیە بە ناونیشانی(زانیاری و بۆچوون لە سەر پەرکەم(فێ) لە ناو خەڵکانی کورد لە کوردستان/باکوری عیراق) کە لە لایەن زانکۆی برونێڵ ئەنجام دەدرێ بە سەرپەرشتی " نەشمیل سەرگەڵویی" وەك بەرپرسی لێکۆڵەرەوە.ئامانجی بەرفراوانی ئەم پرۆگرامی لێکۆڵینەوەیە بۆ دۆزینەوەی ئەوەیە کە بزانرێت چەند لەبارەی پەرکەم ەوە دەزانیت و ڕات چی یە لە سەر کەسانی تووشبوو بەم نەخۆشی یە. بە تایبەتیش پێم ووتراوە کە کە داوام لێ دەکرێ کە ڕاپرسییەك پڕبکەمەوە. ئەم بەشە لە ١٠ دەقیقە زیاتر ناخایەنێت بۆ تەواوکردن.

پێم ڕاگەیەنراوە کە وەڵامەکانم بە تەواوەتی بە شێوەیەکی نهێنی دەمێنێتەوە. ئەوەش دەزانم کە لە هەرکاتێکی پڕکردنەوەی ئەم فۆرمەدا من ئازادم کە بڵێم ناتوانم یان نامەوێت بەردەوام بم، من ئازادم وازبێنم بێ هیچ دەرئەنجامێکی سەلبی و خراپ. بەشداری کردنیشم لەم لێکۆڵینەوەیەدا بە تەواوەتی خۆبەخشانەیە و لەوانەیە لەهەرکاتێکدا پاشەکشێ بکەم. پاشەکشەکردنم نابێتەهۆی هیچ سزایەکی ئەکادیمی یان هەرجۆرێکی تر. ناوم پەیوەست ناکرێ بە بابەتەکانی لێکۆڵینەوەکە، چونکە لێکۆڵەرەوەکە دەیەوێت بزانێت کە تێگەیشتنی خەڵك بۆ پەرکەم(فێ) و چۆن سەیر دەکرێت لەلایەن خەڵکی کوردەوە لە عیراق بەگشتی- نەك زانیاری شخصی وبۆچوونی تاکەکەسێك بە تایبەتی. ڕێگام پێدراوە کە پرسیاربکەم لە بارەی شێوازوڕێگەی لێکۆڵینەوەکە و وەك پێویست وەڵامم دراوەتەوە. پێم ووتراوە کەهەر پرسیارێکم کە پەیوەندی بە پرۆژەکەوە هەیە، دەتوانم ئازادانە هەیە بە گشتی لە بارەی ئەم پرۆژەیە یان کێشەیەکی ڕەوشتی . ئەگەر هەر گلەیی یان nashmel.sargalo@brunel.ac.ukپەیوەندی بکەم بە نەشمیل سەرگەڵویی لە ڕێگای ڕەخنەیەکم هەبێ لەبارەی شێوازی بەڕێوەچوونی لێکۆڵینەوەکە یان بە ئەنجام گەیاندنی دەتوانم پەیوەندی بکەم بە یەکێك taeko.wydell@brunel.ac.uk لە ڕێگای Taeko Wydellلە بەرپرسانی لێکۆڵینەوەی دەروونناسی پرۆفیسۆر . tara.marshall@brunel.ac.uk لە ڕێگای Tara Marshallیان دکتۆر

ئەم ڕێ پێدانی بەشداربوونەی سەرەوەم خوێندەوە و تێیگەیشتم. ئیمزاکەم نابێتە هۆی دەستبەرداربوونم لە مافە یاساییەکانم. دواتریش دەتوانم کە کۆپییەکی ئەم فۆرمە وەك تۆمارێك لای خۆم هەڵگرم.

....	....	....
ئیمزای بەشداربوو	ناوی بەشداربوو	بەروار

بە دوورودرێژی شێوازی لێکۆڵینەوەکەم شی کردەوە و پێناسە کرد بۆ ئەم بەشداربووەی لای سەرەوە و ئەویش ڕازیی بوو کە بەشداری بکات. دواتریش دەتوانم کە کۆپییەك لەم نوسراوی ڕێ پێدانە وەك تۆمارێك لای خۆم هەڵگرم.

....	....	....
ئیمزای سەرپەرشتیاری لێکۆڵەرەوە	ناوی لێکۆڵەرەوە	بەروار

10.20. Debriefing Form- People without Epilepsy – Kurdish – Study 3

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زانیاری و بۆچوون لە سەر پەرکەم(فێ) لە ناو خەڵکانی کورد لە کوردستان/باکوری عیراق

ئامانجی ئەم توێژینەوەیە بۆ گەڕانە بەدوای بۆچوونی خەڵك و هەڵسوکەوتیان بەرامبەر ئەو کەسانەی کە نەخۆشی پەرکەم یان هەیە.

بەڵگەنامەکان دەیسەلمێنن کە ئەو خەڵکانەی کە زانیاری باشتریان هەیەلەسەر نەخۆشی پەرکەم، زیاتر قبوڵی ئەو کەسانە دەکەن کە تووشبوون بەم نەخۆشی یە.

ئەگەر زانیاری زیاترت ویست لەسەر لێکۆڵینەوەکان لەم بوارەدا بگەڕێرەوە بۆ ئەم بابەتانەی لای خوارەوە:

1) ‘‘An epilepsy Questionnaire study of Knowledge and Attitudes in Canadian College Students’’ by Young et al (2002), *Epilepsia*, **43**(6): 652-658.

2) ‘‘Cross-cultural Differences in Levels of Knowledge about Epilepsy’’ by Doughty et al (2003), Epilepsia, **44**(1): 115-123.

3) بۆ زانیاری زیاتر لەسەر پەرکەم(فێ) بە زمانی کوردی ئەم لینکەی خوارەوە بخوێنەرەوە:

http://www.epilepsy.org.uk/sites/epilepsy/files/epilepsyaction_newtoepilepsy_kurdish.pdf

دووبارە زۆر سوپاس بۆ بەشداربوونت لەم توێژینەوە گرنگەدا

Chapter 11: Statistics

11.1. Descriptive statistics for the Seizure Severity measure used including mean, SD, Skewness and Kurtosis

	Seizure Severity item	Mean	SD	Skewness	Kurtosis
1	I feel that my most severe seizures have mostly been: Very Severe; Severe; Mild; Very Mild	.98	.90	.62	-.41
2	Most commonly when I blank out/lose consciousness: I blank out for less than 1 minute; I blank out for between 1 and 2 minutes; I blank out for between 3 and 5 minutes; I blank out for more than 5 minutes; I never blank out/lose consciousness	2.66	1.27	-.64	-.58
3	When I have most severe seizures, I smack my lips, fidget or behave in an unusual way: Always; Usually; Sometimes; Never	1.44	1.22	.01	-1.58
4	After my most severe seizures: I feel very confused; I feel fairly confused; I feel slightly confused; I do not feel confused	.88	1.10	.76	-.81
5	After my most severe seizures, my confusion lasts for: Less than 1 minute; Between 1 and 5 minutes; Between 6 minutes and 1 hour; Between 1 and 2 hours; More than 2 hours; I never feel confused	3.01	1.51	-.31	-.69
6	When I have my most severe seizures: I always fall to the ground; I usually fall to the ground; I sometimes fall to the ground; I never fall to the ground	.92	1.14	.73	-1.05
7	After my most severe seizures: I always have a headache; I usually have a headache; I sometimes have a headache; I never have a headache	1.02	1.14	.59	-1.17
8	After my most severe seizures: I always feel sleepy; I usually feel sleepy; I sometimes feel sleepy; I never feel sleepy	.85	1.07	.81	-.79
9	After my most severe seizures: I always find that I have wet myself; I usually find that I have wet	2.44	.86	-1.55	1.60

	myself; I sometimes find that I have wet myself; I never find that I have wet myself				
10	After my most severe seizures: I always find that I have bitten my tongue; I usually find that I have bitten my tongue; I sometimes find that I have bitten my tongue; I never find that I have bitten my tongue	1.70	1.24	-.34	-1.52
11	After my most severe seizures: I always find that I have injured myself; I usually find that I have injured myself; I sometimes find that I have injured myself; I never find that I have injured myself	2.05	1.03	-.86	-.41
12	After most severe seizures(other than biting my tongue) I can usually return to doing what I am doing in: Less than 1 minute; Between 1 and 5 minutes; Between 6 minutes and 1 hour; Between 1 to 2 hours; More than 2 hour	2.50	1.30	-.28	-1.14

11.2. Descriptive statistics for Knowledge of Epilepsy items reporting the mean, SD, Skewness and Kurtosis

	Knowledge of Epilepsy items	Mean	SD	Skewness	Kurtosis
1	Epilepsy is always caused by brain damage	.51	.50	-.02	-2.02
2	Epilepsy is not infectious	.89	.31	-2.51	4.34
3	Epilepsy is a symptom of mental illness	.53	.50	-.14	-2.00
4	All people with epilepsy have similar symptoms	.74	.44	-1.13	-.73
5	Almost anyone can have a seizure given the appropriate circumstances	.77	.42	-1.31	-.27
6	An EEG can be used to help diagnose epilepsy	.77	.42	-1.30	-.37
7	If an EEG is abnormal, this is a definite sign of epilepsy	.60	.49	-.43	-1.83
8	An EEG is designed to detect electrical activity from the brain	.82	.38	-1.68	.83
9	All people with epilepsy lose consciousness during seizures	.51	.50	-.02	-2.02
10	An epileptic seizure can be described as a temporary lack of oxygen to the brain	.59	.49	-.36	-1.89
11	Some seizures may last for a matter of seconds and not be noticed by others	.76	.43	-1.24	-.47
12	All seizures affect both sides of the brain	.52	.50	-.09	-2.01
13	Certain forms of brain damage always cause epilepsy	.51	.50	-.023	-2.02
14	A normal EEG means that you do not have epilepsy	.67	.47	-.72	-1.49
15	For most people, doctors can effectively treat epilepsy with drugs	.75	.43	-1.16	-.65
16	All those who start drugs for their epilepsy have to take them for life	.62	.49	-.48	-1.79
17	Increasing the dose of antiepileptic drugs increases the chances of side effects	.75	.43	-1.16	-.65
18	An epileptic seizure can be described as an abnormality in the function of nerve cells in the brain	.82	.38	-1.68	.83
19	For antiepileptic drugs to be successful, they must be taken regularly	.92	.26	-3.24	8.60
20	If you forget to take antiepileptic drug for a day, it is usually OK to take two doses together	.15	.36	1.96	1.88
21	Some people get a warning or feeling shortly before a seizure	.84	.37	-1.84	1.41
22	Blood samples can be used to measure the concentrations of antiepileptic drugs in the system	.70	.46	-.90	-1.21
23	People taking a combination of antiepileptic drugs	.74	.44	-1.09	-.81

	are more likely to have side effects than those taking only one				
24	Most people’s seizures are well controlled soon after starting regular drug treatment	.57	.50	-.28	-1.94
25	It is always helpful to take extra doses of antiepileptic drugs when not feeling well	.76	.43	-1.24	-.47
26	If seizures stop with antiepileptic drugs, this means your epilepsy been cured	.64	.48	-.61	-1.64
27	Few people with a diagnosis of epilepsy are taking antiepileptic drugs	.62	.49	-.48	-1.79
28	Some people have been taught to control their seizures by psychological methods	.55	.50	-.19	-1.99
29	There is no need to continue taking antiepileptic drugs if your seizures stop	.63	.49	-.56	-1.71
30	Brain surgery is still used as a method of preventing seizures	.64	.48	-.59	-1.68
31	Most mothers taking antiepileptic drugs are able to breastfeed	.70	.46	-.84	-1.31
32	Too much alcohol may make seizures more likely	.88	.33	-2.33	3.46
33	Most seizures result in brain damage	.45	.50	.21	-1.98
34	Stress may cause some seizures	.95	.22	-4.06	14.62

11.3. Descriptive statistics for the Depression scale used reporting the mean, SD, Skewness and Kurtosis

	Depression	**Mean**	**SD**	**Skewness**	**Kurtosis**
	During the past week …				
1	I was bothered by things that usually don’t bother me	.85	.97	.86	-.36
2	I did not feel like eating; my appetite was poor	.94	1.12	.75	-.94
3	I felt that I could not shake off the blues even with help from my family or friends	1.0872	1.11	.58	-1.03
4	I felt that I was just as good as other people	1.5101	1.23	.01	-1.60
5	I felt I had trouble keeping my mind on what I was doing	1.3075	1.06	.28	-1.14
	I felt depressed	1.0410	1.16	.67	-1.07
6	I felt that everything I did was an effort	1.4109	1.24	.15	-1.61
7	I felt hopeful about the future	1.52	1.21	.01	-1.55
8	I thought my life had been a failure	.924	1.13	.81	-.87
9	I felt fearful	1.02	1.11	.65	-1.00
10	My sleep was restless	1.25	1.19	.32	-1.44
11	I was happy	1.59	1.11	-.05	-1.35
12	I talked less than usual	.86	.99	.94	-.23
13	I felt lonely	1.17	1.20	.46	-1.35
14	People were unfriendly	.82	1.18	1.04	-.61
15	I enjoyed life	1.57	1.25	-.04	-1.65
16	I had crying spells	1.03	1.11	.62	-1.02
17	I felt sad	1.18	1.15	.42	-1.30
18	I felt that people dislike me	.50	.93	1.81	2.06
19	I could not get "going"	.87	1.08	.86	-.68
20	Options: Rarely or none of the time (less than 1 day); Some or little of the time (1-2 days); Occasionally or moderate amount of time (3-4 days); Most or all of the time (5-7 days)				

11.4. Descriptive statistics for the Perceived Illness Seriousness reporting the mean, SD, Skewness and Kurtosis

	Perceived Illness Seriousness	**Mean**	**SD**	**Skewness**	**Kurtosis**
1	How does your epilepsy affect your life? Not at all; Severely affects my life	6.92	3.12	-.91	-.12
2	How long do you think your epilepsy will continue? A very short time; Forever	8.30	2.50	-1.59	1.94
3	How much control do you feel you have over your epilepsy? Absolutely no control; Extreme amount of control	5.83	3.42	-.15	-1.32
4	How much do you think your treatment can help your epilepsy? Not at all; Extremely helpful	3.75	3.22	.46	-.89
5	How much do you experience symptoms from your illness? No symptoms at all; Many severe symptoms	5.81	3.31	-.48	-.91
6	How concerned are you about your illness? Not at all concerned; Extremely concerned	6.96	3.50	-.85	-.65
7	How well do you feel you understand your epilepsy? Don't understand at all; Understand very clearly	4.02	3.45	.48	-1.05
8	How much does your epilepsy affect you emotionally? (e.g. does it make you angry, scared, upset or depressed?) Not at all affected emotionally; Extremely affected emotionally	5.84	3.43	-.39	-1.09

11.5. Descriptive details of Perceived Stigma reporting the mean, SD, Skewness and Kurtosis

	Perceived Stigma	**Mean**	**SD**	**Skewness**	**Kurtosis**
1	I have been discriminated against in education because of my epilepsy	1.76	1.28	.31	-1.05
2	Sometimes I feel that I am being talked down to because of my epilepsy	1.90	1.32	.11	-1.25
3	Having epilepsy has made me a more understanding person I do not feel bad about having epilepsy	1.37	1.10	.65	-.44
4	I worry about telling people I receive epilepsy treatment	1.72	1.21	.17	-1.09
5	Some people with epilepsy are dangerous	1.80	1.30	.02	-1.33
6	People have been understanding of my epilepsy	1.51	1.14	.40	-.71
7	I have been discriminated against by police because of my epilepsy	1.67	1.12	.48	-.74
8	I have been discriminated against by employers because of my epilepsy	1.35	1.11	.73	-.16
9	My epilepsy has made me more accepting of other people Very often I feel alone because of my epilepsy	1.94	1.30	.12	-1.16
10	I am scared of how other people will react if they find out about my epilepsy	1.56	1.01	.39	-.62
11	I would have had a better chances in life if I had not had epilepsy	2.32	1.11	-.31	-.86
12	I do not mind people in my neighbourhood knowing I have epilepsy	2.07	1.20	-.27	-1.09
13	I would say I have epilepsy if I was applying for a job	2.55	1.17	-.52	-.75
14	I worry about telling people about my epilepsy People's reaction to my epilepsy make me keep myself to myself	1.73	1.25	.27	-1.11

15	I am angry with the way people react to my epilepsy	1.70	1.17	.20	-1.06
16	I have not had any trouble from people because of my epilepsy	2.00	1.22	-.23	-1.14
17	I have been discriminated against by health professionals because of my epilepsy	2.00	1.16	-.046	-1.02
18	People have avoided me because of my epilepsy	2.07	1.13	-.002	-.92
19	People have insulted me because of my epilepsy	1.82	1.18	.36	-.98
20	Having epilepsy has made me a stronger person	1.50	1.15	.65	-.50
21	I do not feel embarrassed because of my epilepsy	1.71	1.17	.25	-.97
22	I avoid telling people about my epilepsy	1.74	1.30	.40	-1.05
23	Having had epilepsy makes me feel life is unfair	1.45	1.05	.41	-.66
24	I feel the need to hide my epilepsy from my friends	1.58	1.19	.37	-.91
25	I find it hard telling people I have epilepsy	1.82	1.20	.05	-1.08
26		1.93	1.22	.05	-1.05
27		1.54	1.19	.33	-1.01
28		1.90	1.32	.08	-1.29

With options of: Strongly agree; Agree; Neither agree nor disagree; Disagree; Strongly disagree

11.6. Descriptive statistics for Quality of Life reporting the mean, SD, Skewness and Kurtosis

	Quality of Life	**Mean**	**SD**	**Skewness**	**Kurtosis**
	How much of the time during the past 4 weeks …				
1	Did you have a lot of energy?	52.18	28.84	.14	-.94
2	Have you felt downhearted and low? 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	49.50	32.13	-.11	-1.10
3	How much of the time in the last 4 weeks your epilepsy or antiepileptic drug caused trouble with driving (or other transportation): A great deal; A lot; Somewhat; Only a little; Not at all	53.80	41.94	-.09	-1.69
	How much do your work limitations bother you?				
	How much do your social limitations bother you?				
4	How much do your memory difficulties bother you?	52.07	39.20	-.04	-1.55
5	How much do physical effects of antiepileptic drugs bother you?	52.18	38.88	-.12	-1.52
6		40.27	34.00	.31	-1.19
7	How much do psychological effects of antiepileptic drugs bother you? Not at all bothersome; Only a little; Somewhat; A lot; Extremely bothersome	53.94	37.17	-.13	-1.39
8	How afraid are you of having a seizure during the next 4 weeks? Very afraid; Somewhat afraid; Not very afraid; Not afraid at all	53.45	38.36	-.08	-1.50
	How has your quality of life been during the past 4 weeks (that is, how have things been going for you)? Very good: could hardly have been better; Pretty good; Good & bad about equal; Pretty bad; Very bad: could hardly have been worse				
9		40.52	38.11	.36	-1.32
10		56.83	24.79	-.50	-.03

11.7. Descriptive statistics for Knowledge of Epilepsy items reporting the mean, SD, Skewness and Kurtosis for People without Epilepsy (PWOE)

	Knowledge of Epilepsy items	**Mean**	**SD**	**Skewness**	**Kurtosis**
1	Epilepsy is always caused by brain damage	.49	.50	.04	-2.01
2	Epilepsy is not infectious	.94	.24	-3.72	11.90
3	Epilepsy is a symptom of mental illness	.57	.50	-.28	-1.93
4	All people with epilepsy have similar symptoms	.63	.48	-.55	-1.70
5	Almost anyone can have a seizure given the appropriate circumstances	.62	.48	-.51	-1.75
6	An EEG can be used to help diagnose epilepsy	.82	.38	-1.70	.89
7	If an EEG is abnormal, this is a definite sign of epilepsy	.58	.49	-.32	-1.91
8	An EEG is designed to detect electrical activity from the brain	.86	.35	-2.09	2.40
9	All people with epilepsy lose consciousness during seizures	.38	.49	.48	-1.78
10	An epileptic seizure can be described as a temporary lack of oxygen to the brain	.38	.49	.48	-1.78
11	Some seizures may last for a matter of seconds and not be noticed by others	.77	.42	-1.33	-.24
12	All seizures affect both sides of the brain	.54	.50	-.17	-1.98
13	Certain forms of brain damage always cause epilepsy	.51	.50	-.02	-2.01
14	A normal EEG means that you do not have epilepsy	.53	.50	-.14	-1.99
15	For most people, doctors can effectively treat epilepsy with drugs	.69	.47	-.78	-1.40
16	All those who start drugs for their epilepsy have to take them for life	.52	.50	-.08	-2.01
17	Increasing the dose of antiepileptic drugs increases the chances of side effects	.75	.43	-1.14	-.70
18	An epileptic seizure can be described as an abnormality in the function of nerve cells in the brain	.84	.36	-1.91	1.68
19	For antiepileptic drugs to be successful, they must be	.81	.39	-1.59	.53

	taken regularly				
20	If you forget to take antiepileptic drug for a day, it is usually OK to take two doses together	.13	.33	2.26	3.11
21	Some people get a warning or feeling shortly before a seizure	.73	.44	-1.06	-.87
22	Blood samples can be used to measure the concentrations of antiepileptic drugs in the system	.63	.48	-.55	-1.70
23	People taking a combination of antiepileptic drugs are more likely to have side effects than those taking only one	.74	.44	-1.08	-.83
24	Most people’s seizures are well controlled soon after starting regular drug treatment	.65	.48	-.66	-1.58
25	It is always helpful to take extra doses of antiepileptic drugs when not feeling well	.73	.44	-1.05	-.91
26	If seizures stop with antiepileptic drugs, this means your epilepsy been cured	.75	.43	-1.14	-.70
27	Few people with a diagnosis of epilepsy are taking antiepileptic drugs	.45	.50	.19	-1.98
28	Some people have been taught to control their seizures by psychological methods	.53	.50	-.13	-2.00
29	There is no need to continue taking antiepileptic drugs if your seizures stop	.58	.49	-.335	-1.90
30	Brain surgery is still used as a method of preventing seizures	.38	.49	.48	-1.78
31	Most mothers taking antiepileptic drugs are able to breastfeed	.55	.50	-.19	-1.98
32	Too much alcohol may make seizures more likely	.73	.44	-1.06	.87
33	Most seizures result in brain damage	.53	.50	-.11	-2.00
34	Stress may cause some seizures	.90	.31	-2.60	4.79
	Total	21.26	4.98	.18	-.78

Crohnback’s alpha= .740

11.8. Descriptive statistics for Stigma Scale of Epilepsy (SSE) items reporting the mean, SD, Skewness and Kurtosis for People without Epilepsy (PWOE)

	Stigma Scale of Epilepsy (SSE)	Mean	SD	Skewness	Kurtosis
1	Do you think people with epilepsy feel able to control their own epilepsy?	3.14	.83	-.83	.43
2a	What do (would) you feel when you see (if you saw) an epileptic seizure? a) Shock	1.92	.90	.37	-.37
2b	What do (would) you feel when you see (if you saw) an epileptic seizure? b) Fear	1.96	.89	.36	-.53
2c	What do (would) you feel when you see (if you saw) an epileptic seizure? c) Sadness	2.55	.96	-.22	-.82
2d	What do (would) you feel when you see (if you saw) an epileptic seizure? d) Pity	2.48	1.03	-.174	-1.02
3a	What difficulties do you think people with epilepsy have in their lives? a) Family	2.22	.98	-.15	-.84
3b	What difficulties do you think people with epilepsy have in their lives? b) Work	2.62	.91	-.34	-.44
3c	What difficulties do you think people with epilepsy have in their lives? c) School	2.61	.87	-.29	-.42
3d	What difficulties do you think people with epilepsy have in their lives? d) Social relationships	2.44	.84	-.06	-.60
3e	What difficulties do you think people with epilepsy have in their lives? e) Sexual	2.23	.96	.02	-.49
3f	What difficulties do you think people with epilepsy have in their lives? f) Emotional	2.42	.92	.040	-.84
3g	What difficulties do you think people with epilepsy have in their lives? g) Prejudice	2.25	1.07	.10	-1.02
4a	How do you think people with epilepsy feel? a) Worried	2.21	.978	.03	-.50
4b	How do you think people with epilepsy feel? b) Dependent	2.27	.96	.19	-.78
4c	How do you think people with epilepsy feel? c) Incapable	2.18	.91	.30	-.65

4d	How do you think people with epilepsy feel? d) Fearful	2.18	.90	.33	-.43
4e	How do you think people with epilepsy feel? e) Ashamed	2.15	.95	.25	-.73
4f	How do you think people with epilepsy feel? f) Sad	2.42	.87	-.06	-.73
4g	How do you think people with epilepsy feel? g) No different	3.12	1.06	-1.10	.33
5a	In your opinion, in which situation does prejudice against epilepsy occur: a) Social relationships	2.15	.97	.15	-.70
5b	In your opinion, in which situation does prejudice against epilepsy occur: b) Marriage	2.14	1.00	.25	-.94
5c	In your opinion, in which situation does prejudice against epilepsy occur: c) Work	2.50	.91	-.04	-.69
5d	In your opinion, in which situation does prejudice against epilepsy occur: d) School	2.40	.95	.05	-.94
5e	In your opinion, in which situation does prejudice against epilepsy occur: e) Family	2.16	.98	.42	-.86
	Total	45.82	14.87	.22	-.24

Crohnbach’s alpha= .848

11.9. Socio-demographic characteristics for all participants with Epilepsy

	UK		Total n (%)	Kurdish		Total n (%)
	n	**%**		**n**	**%**	
Gender						
Male	27	32.1%	84 (100%)	40	45.5%	88 (100%)
Female	55	67.9%		48	54.5%	
Marital Status						
Single	39	46.4%		34	38.6%	
Married	32	38.1%		45	51.1%	
Divorced	8	9.5%		1	1.1%	
Widowed	2	2.4%		–	–	
Living with Partner	2	2.4%		–	–	
Separated	1	1.2%		–	–	
Missing	–	–		8	9.1%	
Occupation						
Student	3	3.6%		8	9.1%	
Teacher/Lecturer	3	3.6%		3	3.4%	
Office Worker	11	13.1%		–	–	
Civil Servant	1	1.2%		11	12.5%	
Housewife/Husband	–	–		25	28.4%	
Unemployed	8	9.5%		14	15.9%	
Other	32	38.1%		19	21.6%	
Missing	26	31%		8	9.1%	
Education						
Illiterate	1	1.2%		17	19.3%	
Primary School	1	1.2%		22	25.3%	
Secondary School	26	31%		38	43.2%	
Diploma	14	16.7%		4	4.5%	

Undergraduate	22	26.5%	6	6.8%
Postgraduate	11	13.1%	–	–
Missing	9	10.7%	1	1.1%
Diagnosis Period (years)				
0-5	10	11.9%	23	26.1%
6-10	11	13.1%	19	21.6%
11-20	14	16.7%	22	25%
20 +	44	52.4%	19	21.6%
Missing	5	6%	5	5.7%

11.10. Socio-demographic characteristics for all participants without epilepsy

	n	%	Total n (%)
Group			
UK	116	36.7%	316 (100%)
Kurdistan	200	63.3%	
Age			
Mean	34.3		
Minimum	18		
Maximum	73		
Gender			
Male	114	36.1%	
Female	201	63.6%	
Missing	1	.3%	
Marital Status			
Single	125	39.6%	
Married	160	50.6%	
Divorced	14	4.4%	
Widowed	5	1.6%	
Living with Partner	3	.9%	
Separated	0	n/a	
Missing	9	2.8%	
Occupation			
Student	55	17.4%	
Teacher/Lecturer	65	20.6%	
Office Worker	22	7%	
Civil Servant	35	11.1%	

Housewife/Husband	12	3.8%
Unemployed	2	.6%
Other	92	29.1%
Missing	33	10.4%
Education		
Illiterate	2	.6%
Primary School	15	4.7%
Secondary School	93	29.4%
Diploma	64	20.3%
Undergraduate	88	27.8%
Postgraduate	42	13.3%
Missing	12	3.8%

11.11. Collinearity Statistics for the UK and Kurdistan group with epilepsy

Vrariables	**Tolerance Values**	**VIF**
1.Group	.22	4.63
2. Age	.77	1.30
3. Gender	.95	1.05
4. Seizure Severity	.84	1.20
5. Knowledge of Epilepsy	.24	4.24
6. Perceived Illness Seriousness	.63	1.60
7. Depression	.59	1.70
8. Perception of Stigma	.73	1.40

Chapter 12: Participant Demographics

Kurdistan Participants					UK Participants				
Participant No.	**Gender M/F**	**Age**	**Length of Diagnosis (years)**	**Length of Interview Min:sec**	**Participant No.**	**Gender M/F**	**Age**	**Length of Diagnosis (years)**	**Length of Interview Min:sec**
1	F	24	8	29:39	1	F	27	8	14:47
2	M	30	19	18:26	2	F	48	1.5	20:22
3	M	36	9	11:05	3	F	70	63	20:47
4	F	43	12	22:24	4	M	41	28	18:09
5	M	21	15	12:18	5	F	44	35	24:51
6	F	38	10	11:38	6	F	58	26	21:32
7	F	25	4	12:35	7	M	26	10	10:32
8	F	44	25	10:30	8	F	46	7	22:16
9	M	42	3	9:16	9	F	21	21	7:48
10	M	18	2	9:21	10	M	66	53	22:21

Chapter 13: Transcripts

13.1. UK Participant 1

UK Interview 1 F

Interviewer: How old are you?

Participant: 27

Interviewer: 27, what is your marital status?

Participant: I'm not married (laughs)

Interviewer: You're not married?

Participant: I'm not single either

Interviewer: cohabiting?

Participant: Yes

Interviewer: Do you have any dependant?

Participant: Yeah, two children

Interviewer: How old are they?

Participant: 5 and 2 months

Interviewer: How long have you had epilepsy?

Participant: Erm, it's been diagnosed about 10 years now

Interviewer: 10 years, so you were 16 then?

Participant: No I was 19 so 8 years

Interviewer: Do you know other people with epilepsy?

Participant: Yes one, Honey

Interviewer: What were the circumstances around your diagnoses, so what happened around then?

Participant: I kept fitting

Interviewer: Daytime or …?

Participant: Yeah, erm, so I had to go and have it checked out

Interviewer: Any particular reason? Anything happen around that time?

Participant: Stress, tiredness, eating, all those things combined

Interviewer: Do you have anyone else in the family..?

Participant: No just me

Interviewer: So how did you feel when you were diagnosed? When you were told it was epilepsy?

Participant: Scared, terrified (laughs), erm, but I knew it could be sorted out and controlled so it wasn't too bad.

Interviewer: What was your knowledge of epilepsy before diagnosis?

Participant: I didn't have any

Interviewer: Nothing at all?

Participant: No just that people fit and that was about it

Interviewer: How confident are you about your knowledge now on epilepsy?

Participant: Oh yeah I'm confident

Interviewer: Yeah? You're an expert?

Participant: (Laughs) yeah

Interviewer: That's good. What type of support did you get from your family and friends?

Participant: Not a lot

Interviewer: No?

Participant: No (laughs)

Interviewer: How come?

Participant: Because I wasn't talking to my family at the time so … (laughs)

Interviewer: So you were on your own dealing with it?

Participant: Yeah (laughs)

Interviewer: Ok, what about your friends?

Participant: Erm, they didn't really know much about it either, they just sort of said 'you're not going to fit in front of me are you?'

Interviewer: That's nice

Participant: (Laughs) really supportive

Interviewer: How are you now, do you get regular fits or …?

Participant: Erm, yeah it's managed so maybe twice a year, three times a year

Interviewer: That's good, you're on medication?

Participant: Yeah

Interviewer: Were you still on medication when you were pregnant?

Participant: Yeah

Interviewer: And that was fine?

Participant: That's fine

Interviewer: Do you have any feelings before a seizure? Do you feel anything come on?

Participant: I do I get erm, floaters

Interviewer: Ok

Participant: Erm

Interviewer: And what are they like?

Participant: They're like stars, usually, like silver dots just floating across my eyes, erm, and just generally out of it, I don't feel, it's almost like I'm not here but I'm here, erm, so I know what's going on around me but I can't interact with what's going on around me, it's really strange, strangest feeling

Interviewer: How long do they last for? Your seizures

Participant: Not long, erm, a few minutes, and then they pass

Interviewer: Do you think there's anything that triggers your attacks?

Participant: Yeah, tiredness is one, stress is another one, not eating is another one, all three of those combined (laughs) doesn't bode well

Interviewer: How do you feel after a seizure?

Participant: Shattered, so tired erm, I'm in pain as well

Interviewer: What sort of pain?

Participant: Just all my muscles, I feel like I've done a 200 mile marathon (laughs) erm, because where the muscles are contracting its really sore

Interviewer: How long do you have those aches for?

Participant: It can last for 24 hours, depending on how bad, because I have different types of seizures, so depending on how bad the seizure is erm, it can last up to 24 hours, but I'm just like …

Interviewer: What about those around you, what do they do when you have a seizure?

Participant: Erm, what while I'm having one?

Interviewer: Yeah

Participant: Nothing really, just make sure there's nothing around me that can hurt me, erm, and leave me to it until I come out of it

Interviewer: What do you think they feel when they see you having a seizure, your loved ones?

Participant: Worried, scared, erm, probably about it really (laughs)

Interviewer: How do you feel when they have those feelings?

Participant: Guilty (laughs), 'I'm sorry'

Interviewer: Do you think that you can control your seizures; do you have any control over them?

Participant: No

Interviewer: No?

Participant: No, the only control I have is the medication, if I'm going to have one I'm going to have one, there's nothing I can do to stop it, erm, if I feel it coming on then I get, well sometimes, most of the time I can get to a safe place like the bed or sit down on the floor or something but I can't control it

Interviewer: How long do you have before …?

Participant: Minutes, it's literally a matter of minutes, so …

Interviewer: Have you fallen on the ground and hurt yourself?

Participant: I've not hurt myself but I have fallen, erm, which wasn't nice

Interviewer: No I can imagine

Participant: Erm, don't remember falling but apparently I fell (laughs)

Interviewer: How did you begin to cope with being an epileptic?

Participant: I just took the tablets

Interviewer: Did you, emotionally how did you …?

Participant: I got upset, I did get upset for quite a long time erm, I didn't know why I had epilepsy, erm, and then I found out why I got epilepsy which made me more upset, so ...

Interviewer: Why? What was the reason they gave you?

Participant: Erm, my mother drank a lot when she was pregnant with me and the doctors have said that that's what probably has caused the scarring on my brain, which has caused the epilepsy, so I was very angry with her erm, and it took me a long time to sort of get over that, but erm, yeah I just, in the end I thought well what's happened has happened, nothing I can do about it so I'm just going to have to carry on taking the medication and get on with it

Interviewer: Do you feel having more knowledge yourself helped you deal with it?

Participant: Yeah, yeah, I researched a lot about it and I asked a lot of questions about it

Interviewer: Doctors?

Participant: Yeah, erm, because in my mind if I knew more about it then I had more, not control over it but I had more understanding of what was happening to me which made it easier to deal with

Interviewer: Ok

Participant: So …

Interviewer: Do you feel you can tell people you have epilepsy?

Participant: Yeah it doesn't bother me

Interviewer: It doesn't?

Participant: Na

Interviewer: Do you think your life has changed because of epilepsy?

Participant: Erm, I have to be more careful, erm, obviously I can't burn the candle at both ends for too longer, erm, I have to take the tablets, I have to make sure that I eat properly in the day and at night so my sugar levels don't go so low my body can't cope with it, erm, I get my days sometimes when I don't feel right and I just have to take it easy but that's about it really

Interviewer: How has epilepsy affected your outlook on life?

Participant: I won't let it beat me, it's not going to control my life, that's about it

Interviewer: So you feel that everything would have been the way it is even if you didn't have epilepsy?

Participant: Yeah

Interviewer: Do you think people would treat you differently if they knew you had epilepsy?

Participant: Some people may be

Interviewer: What sort of circumstances would they be?

Participant: People could be worried I'm going to have a fit and be bit more hmm, but usually people aren't any different so …

Interviewer: Is there anything that you can't do because of epilepsy?

Participant: Can't drive

Interviewer: Can't drive?

Participant: Can't drive yet

Interviewer: Ok, do you think you will be able to?

Participant: Hopefully (laughs)

Interviewer: What are the regulations?

Participant: You have to be fit free for, I think it's for a year

Interviewer: Ok

Participant: And it's coming to a year now

Interviewer: Oh congratulations

Participant: So if I can get through next month then I can get my provisional license and I can start driving

Interviewer: I wish you luck, something to look forward to

Participant: Thank you (laughs)

Interviewer: How do you think epilepsy is perceived in the UK generally?

Participant: People are pretty easy going about it, erm, it's the people that know nothing and those are the ones that back off from you, erm, because they think you're going to drop on the floor at any given moment and fit and they're not going to know what to do but generally most people are okay about it

Interviewer: What is the most difficult aspect of having epilepsy, apart from driving, not being able to drive?

Participant: Erm, flashing lights, that is the worst thing ever for me, its flashing lights, so, you know I don't go out clubbing now but erm, when I used to go out clubbing I used to have to be very, very careful about where I went, erm, because obviously the lights affect me, it was awful, horrible

Interviewer: Would it make you have a fit?

Participant: Sometimes, a lot of the time, erm, and if it didn't make me fit it would make me feel really, really, really bad erm, very light headed, the whole place is spinning, horrible

Interviewer: What about TV, the computer, you ok with that?

Participant: Erm, yeah, I can't, I'm not, it depends like the TV, it depends what it is.

Interviewer: Hmm

Participant: So, say the police programme, I'm ok watching them as long as the lights on, if the lights off and the blue lights are going that makes me feel really bad, erm, if there's anything quick moving on TV and the lights are off that makes me feel bad, erm, the computer I don't spend a lot of time on but it tends to give me a headache, I don't spend too much time on the computer anyway

Interviewer: Right, it wouldn't make you have a seizure would it?

Participant: I haven't done but I've not really tested it out (laughs) to see

Interviewer: That's good. What advice would you give to those who are newly diagnosed?

Participant: Take the tablets, take the tablets and be patient because the first lot of tablets aren't always the ones that work, erm, and don't think that you can't do anything in like, life has to stop because it doesn't, as long as you get that right level of medication and the right medication you'll be absolutely fine, carry on as normal, as long as you take those tablets then happy days, you'll be fine

Interviewer: Where would you direct them to go for support?

Participant: The hospital, and family and friends if they've got, if I had decent family and friends around me it wouldn't have taken me so long to get used to the idea erm, and the internet, look it up, find out what's going on, find out why, you know, what part of your brain has got the scarring on or whatever, why you know, what happens when you fit, you know why your brain is almost like short circuiting, erm, because when you know why, if you know what's happening you can understand it a bit better you can deal with it a bit better

Interviewer: So it's more understanding that would help you deal with it?

Participant: Yeah

Interviewer: Do you have anything to add about epilepsy, how to deal with it or from your experiences?

Participant: Yeah just don't let it affect your life too much, carry on doing what you're doing, just know your triggers, if you know your triggers then that's really handy, really handy to know your triggers

Interviewer: How would you find out what your triggers are, do the hospitals tell you or do you find that out from …?

Participant: Its literally like, for me, every time I got to a really tired point where I felt so tired you know, I hadn't slept for a week or something and I hadn't eaten for a week or you know something like that, hadn't eaten properly all day erm, or at all day, you just find a pattern, so you know you don't sleep properly for two weeks you're burning the candle at both ends you're going out raving every night and then you're going to work all day in the day, you know you get up early going to bed late and then you have a fit you find a pattern as to what's happening, once you find that pattern that's when you can think 'oh, okay so I've been really tired this week and now I've had a fit' and then the next time 'oh I've been really tired again and I've had a fit' you find your triggers like that, that's how I did it, I found my triggers like that

Interviewer: And you don't feel that it hold you back or anything during the day or week?

Participant: If I fit then it does, if I've had a fit then it holds me back erm, especially with the kids, I can't do anything with them, erm, but on a daily basis when I don't fit doesn't really no, you just got manage your life around it a bit.

Interviewer: Ok, well thank you very much

Participant: That's ok

Interviewer: Thank you

End of interview

13.2. UK participant 2

UK Interview 2

Interviewer: How old are you?

Participant: 48

Interviewer: And what is your marital status?

Participant: Married

Interviewer: Do you have any dependants?

Participant: Does dependants mean they still live at home?

Interviewer: Yes

Participant: Only if they live at home?

Interviewer: No you can say others …

Participant: Oh I've got 3 children but 2 live at home

Interviewer: 2 live at home? Ok, how old are they?

Participant: 24, 22 and 17

Interviewer: And how long have you had epilepsy?

Participant: I've been diagnosed about 18 months

Interviewer: And what was the erm, what was happening around that time?

Participant: What do you mean?

Interviewer: Was there anything significant that happened or did it just come on suddenly?

Participant: I'd had a couple of collapses but nobody had been with me so nobody knew why so I was taken into hospital. They did suspect I'd had a stroke, erm, I've got white matter on my brains that made them think I'd had a stroke, I was kept in but then they decided it wasn't, then it was only when I was at work and fell down the stairs and somebody had witnessed me having the seizure that they then diagnosed it as epilepsy.

Interviewer: Do you know other people with epilepsy?

Participant: I didn't then, I do now (laughs), I didn't before, no.

Interviewer: How did you feel when you first diagnosed with epilepsy?

Participant: Erm, I think it was a bit of a relieve to know why, because I actually had no memory of the time before the seizure and the time afterwards so I think it was just 'well now we know what we're dealing with' but I'm quite a positive person.

Interviewer: That's good to know

Participant: Yeah (laughs), that's erm, that's how I would deal with it generally so it's not particularly because it was that it's just how I am.

Interviewer: And you continued with your work?

Participant: No I'm signed off work.

Interviewer: Ok

Participant: I've got be 6 months seizure free before I can return to work so …

Interviewer: What was your knowledge of epilepsy before your diagnosis?

Participant: I knew what epilepsy was, I knew there was quite a few different types of seizures but I'd never seen anybody have a seizure, erm, I knew what to do if somebody had a seizure like a tonic-clonic one but I'd never had to do that, maybe because I work with families and children it's something I had in training so that's why.

Interviewer: How confident are you on your knowledge of epilepsy now that you've had it yourself?

Participant: I think I know a lot more but I'm not obsessed with it (laughs) like some people, do you know what I mean it's not, it doesn't define me and I've got it but I don't need to know everything about it.

Interviewer: So you know enough to help you?

Participant: Yeah, yeah I don't really … and to help other people that I now know with epilepsy but it's not all consuming for me like some people.

Interviewer: Ok. What type of support did you get from family and friends?

Participant: Oh fantastic, yeah. They worry more than me because it's not stopped me doing anything so we have a system so if I have a seizure, I wear this for my mum and dad (shows me bracelet), my immediate family are extremely relaxed about me but my mum and dad worry about me so if I have a seizure my netti alert bracelet, so that the paramedics, or whoever finds me rings them, they have all my details and usually they would ring my husband but he's probably busy at work and wouldn't answer the phone (laughs) then they might usually get my dad because he's retired and then they have a way so my dad would ring my mum, my mum would ring my kids, my kids would then ring my Lean, Joanna, Yolanada, Jamima and there's like a tree of …

Interviewer: People you need to know?

Participant: Yeah, and I never, I tell everybody whenever I've had one because I think 'well there's no point', not telling people because they're going to worry, I've had one everybody knows, I always end up in hospital and then I try and escape as quickly as I can.

Interviewer: Why do you always end up in hospital?

Participant: Because I'm always out and about

Interviewer: Oh dear.

Participant: I always do it very dramatically; I fall down stairs, I'm on escalators in (large department store).

Interviewer: You just want to show people?

Participant: Exactly (laughs), but I've you know, it's just always quite dramatic when I have my... So, my mum …

Interviewer: Because you're so relaxed?

Participant: Yeah my mum has a theory that I go out

Interviewer: Before you have a seizure?

Participant: Yeah the only thing is I am quite a busy person out and about, but the only thing I really wouldn't particularly want is for somebody to come home and find me so maybe there is a sort of sense that I go out and I am the type of person who, last week me and my husband, we were only walking and there's a man in the river, trying to kill himself, so I tend to be that person who would help somebody so I think I've always been very lucky, somebody's always helped me and I've made, my postman has knocked on my door every day because he found me one time up at the shops, so I've got you know, made some nice friends out of it, people have found me, you know two nurses found me at Dillon's escalator and they still ring me so …

Interviewer: It's nice to get that support

Participant: Yeah, yeah, I'm lucky really, I've got nice friends

Interviewer: Do you have any feelings before you get a seizure?

Participant: If I do I don't remember them. I think I must do but I lose sort of about half an hour before

Interviewer: And this is every time?

Participant: Hmm. So like the time I was in Harrow, I knew I was in Harrow shopping but I didn't actually remember going into Dillon's, so when I was, I was like 'where was I? But I don't remember going into Dillon's' obviously I did because that's where I was.

Interviewer: What are the sudden signs of your seizures is there anything that triggers them off, do you think?

Participant: I can't think of anything, there's no rhyme nor, first of all, the one thing possibly but it's not every time, is sometimes when I've got a very heavy period, but that's probably out of 10 seizures I've had its probably 5 of them but not enough to for my neurologist to feel there's a pattern, I don't know

Interviewer: How do you feel after a seizure?

Participant: Like I've ran 10 marathons

Interviewer: And how long does that last for?

Participant: Well, my, people laugh because sometimes they make me stay in hospital because I have a load and then I usually come home and then I sleep for 24 hours and then I have a dressing gown day because I don't get tempted to do, I want to be up because that's me and I would be like 'oh I'm going to make the dinner' and I'm stumbling around in my dressing gown, and then the next day I have to get out because I'm a bit … but I am really tired still and by about the fourth day I'm sort of getting back to normal.

Interviewer: How often do you get seizures now?

Participant: Well I'm a very high dose of medication now, because my last one was about 3 months ago, it's very good and that was my last one.

Interviewer: Excellent, well that's good.

Participant: That's how I think …

Interviewer: What do those around you do when you have a seizure?

Participant: I had one in the middle of a fireworks display, we were there with about 20 of our friends who were all there, kids, they just called an ambulance, and it had to trek across the field and yeah, stopped the firework display but then it was a rotary organised and they sent me a beautiful bouquet of flowers, so they didn't need to do that and I spoilt their firework display (laughs), so yeah, no I've never had any experience of anybody being, erm, generally I'm out so its usually somebody I don't know.

Interviewer: Ok. What do you think people feel when they see you have a seizure? And how does that make you feel?

Participant: Well whoever's found me, I always speak to them, thank them, send them a thank you card, I always feel, and they always feel reassured when they see me afterwards. The thing that I found is that men, my postman still can't over the fact that he had to touch me, move me, yeah, he's lovely. I nominated him for like the postman of the year because he was so lovely and people don't like going in my bag, for my phone to look for numbers, people keep saying 'I'm really sorry but I had to go in your bag' I'm like 'don't be silly its fine, I'm not …' they're more worried about …

Interviewer: Imposing on your privacy?

Participant: Yeah, yeah, yeah.

Interviewer: You don't mind?

Participant: I don't mind, no. I mean sometimes, I mean sometimes people see this (shows me her medical bracelet) not always, it's usually the paramedics that find it.

Interviewer: Ok do you think if people knew about medical braces …?

Participant: Yeah but I think you know people don't like to touch, you know I can understand why people don't, its more for when paramedics come really, they know to look for it.

Interviewer: Do you feel you have control over your seizures?

Participant: No

Interviewer: Not at all? And how did you begin to cope with being an epileptic? What processes did you have to go through within yourself?

Participant: I don't, I did, I just thought that's …

Interviewer: Was it just you accepting it?

Participant: Yeah, I think if I didn't how could I expect everybody else around me to, people are very guided by how I would deal with things and a lot of people were very worried and so there's a lot worse things, for me I think you know I can still, I mean I can't work at the moment but then things happen for a reason so I've got a lot of people, I've joined the group and so I've met a lot of other people perhaps I can help and I just do voluntary work because I can't work, so …

Interviewer: Well that a nice change isn't it, to help others?

Participant: Yeah but that was my work before so it's sort of just doing it and not getting paid really but you know.

Interviewer: So you were in the same line of work before?

Participant: Well I'm working with the elderly at the moment with my voluntary whereas I was working with young families before and its, I had two jobs, one job they made me redundant the other job, they still, my job's there when I want to go back so they've been really good, really supportive, work.

Interviewer: it helps doesn't it?

Participant: Oh yeah, yeah, very much so.

Interviewer: Do you feel that you can tell people that you have epilepsy?

Participant: Yeah

Interviewer: You don't have problems or worries? What sort of circumstances do you tell them?

Participant: Well everybody who knows me now knows, there wouldn't be anybody who, and my medication is right out on display, my alarm goes off for me to take my medication so if I'm out with people in the evening my alarm will go off at 9 o'clock and everybody knows I would take my medication erm, …

Interviewer: Do you think people treat you differently because of your epilepsy?

Participant: The only thing I notice is if I'm not at home people will ring me on my mobile

Interviewer: To make sure that you're taking your medication?

Participant: No not to, to see if I'm ok, and then I'll say 'hello' and they say 'oh, I wasn't ringing to check up on you' but that's their issue really, it's not mine (laughs) and they try and make it sound like they're not worried and they're like 'we're just thinking you weren't at home' I'm like 'no I'm fine' but you know, I'm not, they're more worried than me, I think.

Interviewer: Does it help knowing more people are looking out for you?

Participant: Not really because I feel like I'm having to look after them to tell them alright yeah, (laughs) it's like …

Interviewer: Do you think your outlook on life has changed at all because you have epilepsy?

Participant: Honestly, no

Interviewer: That's good to know. Do you think that there's anything that you can't do …?

Participant: I think I'm quite unusual, because my GP says that, because he says, every time I go in there, he's going, alright I've got a black eye I've got bruises and he's going 'I know what you're going to say Hilary, it's your last one' I'm like 'yes' and so he's got me speaking to some people in the practice who aren't coping so well. So, I know that you know for some people, and because I've, I'm ok with it I don't let, you think I don't understand because I've met some people who've had it for life and they're still not managing, it's just me, me.

Interviewer: Just the way you are.

Participant: Yeah, and I would be like that about

Interviewer: Anything

Participant: Yeah, and so it's, it could be anything that I had. I mean when I was younger I had, they found out, I was very ill, really ill, after I had my second baby and they didn't know what was wrong and I was, and they found out all my insides were the wrong way so they like, everything was like mirror, so I had appendicitis but they didn't know because it was on the other side, if you see what I mean, so when they took it all out I was infected and they had to have my bowl round and tethered down and everything so, I think when you've felt so ill like that, I mean if I have a fit I'm only ill for a few days, the only thing that I don't like is taking medication because it makes me really tired but then I've got used to that but now they think there's something wrong with my heart. So, they're looking into the link whether if something happens to my heart and that causes my seizures. I've had this test which they think it's quite …

Interviewer: Isn't quite normal?

Participant: Yeah, so...

Interviewer: What do you think is the most difficult aspect of having epilepsy?

Participant: Other people worrying about me.

Interviewer: How's epilepsy perceived in the UK?

Participant: Erm, I think it's much better, it's like I went on a visit with my husband's aunt we went to this house and it was actually a home for people who had epilepsy, it was in Buckinghamshire, it was a home and like I think it's a generation thing like she was saying an old aunt wouldn't have had me into her house because she felt people were possessed by the devil if they had seizures, I mean I've not experienced anything like that but I know that that's … and I think even in the UK even cultures, there's a gentleman that comes to our group and none of his family know so even in the UK when you've got other cultures here its, yeah.

Interviewer: What advice would you give to people who are newly diagnosed?

Participant: Talk.

Interviewer: Talk to…?

Participant: People who have got it, people who haven't got it, just be, it's not something to hide, it's just something you can't do anything about so…

Interviewer: Where would you advise them to go for support?

Participant: Erm, (laughs) I suppose I should say the group.

Interviewer: No you can be completely honest

Participant: I would say go to a group that maybe you can get some support from if you felt you needed that, but you need a certain type of help.

Interviewer: Anyone else, anywhere else who you suggest they go to?

Participant: The things is I think some people who look up on websites can find too much information and I've been with people where its frightened them when they've looked up side effects of drugs and sometimes I think too much medical information is too much. And I think people have not got to think of themselves as being that, that’s a small part of their lives and they’re not just, yeah, they’ve got to think beyond that.

Interviewer: Is there anything that you would recommend to help people cope with epilepsy, the diagnosis?

Participant: I think it helps if you’ve got a good consultant, I mean I have a really nice consultant, he suits me, I mean I don’t think he’d suit everybody but he suits me and I think he’s very measured and he told me at the very beginning this is a very long journey to have and some people might not have liked that honesty at the beginning but I think if the medical team are honest with you, because I think you think, the first lot of tablets I took made me feel so ill, I couldn’t function, I couldn’t walk, I couldn’t talk, I couldn’t, and but he was very honest with me he said ‘look we’ll take you off those we’ll give you another drugs’ but if he’d told me at the beginning ‘oh yeah I could sort this out’ and even now he says you know ‘we’re one step further on on that journey’ he’s very honest. I appreciate honesty.

Interviewer: Do you have anything to add that you think might be helpful to me to widen my knowledge or to others to …?

Participant: I think people should think that everybody with epilepsy deals with it in the same way, you know I think there’s a perception of people with epilepsy that they don’t want to go out, that they’re frightened to do things, that, and there are some people that are like that, not everybody, I think people tend to have a, I think you know, they might associate people who have got learning difficulties or have a brain injury, they subsequently have seizures as that type of person who may have, I think people may have an image of somebody with epilepsy, you know, not everybody’s the same.

Interviewer: So you think more …?

Participant: Just anybody can have it, so.

Interviewer: So you think more general information?

Participant: Yeah and I also think every time I go into hospital I, I mean I never used to drink much at all, I used to drink the odd glass of wine, that’s the only thing I don’t like, when I’m in hospital I’m usually between two people who are drunk who are having seizures because they’re withdrawing, and so the assumption is that I, and everybody that comes up to me says ‘have you had a drink today?’ and I don’t even drink now, I wouldn’t, ever since, I’m so tired with the drugs I wouldn’t but there’s an assumption when you go into hospital, coming in an ambulance having had a seizure that I, the alcohol and withdrawing.

Interviewer: The medical profession then?

Participant: Hmm.

Interviewer: A bit of advice for them then not to assume?

Participant: Absolutely yeah, yeah, you know so …

Interviewer: Thank you very much for your time

Participant: That’s alright

End of interview.

13.3. UK participant 3

Interview 3 UK

Interviewer: How old are you, if you don't mind me asking?

Participant: 70

Interviewer: Your marital status?

Participant: Err, well no, I'm divorced.

Interviewer: Do you have any, you don't have any dependants, living at home with you?

Participant: No

Interviewer: What is your occupation or your occupation before?

Participant: I was a (inaudible) ambulance escort.

Interviewer: How long have you had epilepsy?

Participant: 63 years

Interviewer: 63 years? You were 7 years old?

Participant: Yeah

Interviewer: What happened around that time when you were diagnosed? Anything special or particular happen around that time?

Participant: I was diagnosed when I was err dancing (laughs) on the stage in Acton Town hall, I was, it was I used to go to a dancing school, school of dancing in Shepherds bush, we used to do a show every year and they had a show, always in the Acton town hall, I just went up to her to get my certificate and I had my first fit.

Interviewer: It must have been traumatic? And that age as well

Participant: Yeah it was (laughs).

Interviewer: Do you know other people with epilepsy?

Participant: Sorry?

Interviewer: Among your friends, do you know other people with epilepsy?

Participant: A lot of people, yeah, yeah, I didn't know then.

Interviewer: How did you feel when you were first diagnosed, although it's going back quite a bit and you were quite young?

Participant: Well to be truthful I don't really think it made that much of an impression on me because I didn't know what it was all about, everything was kept behind closed doors in those days you erm, I don't think anybody ever called it epilepsy, it was called turns or funny turns or you've had one of those things again, you know there was never, you know the terminology epilepsy was never used really.

Interviewer: Why do you think that was?

Participant: Erm, I don't really think they understood themselves, so erm, I don't think it was done for any reason because erm, no I don't think it was done for any reason at all but erm, but just the terminology wasn't just used

Interviewer: Do you think it had something to do with how society perceived …?

Participant: Oh yeah definitely, because it wasn't prominent, it wasn't prominently known was it, well it wasn't

Interviewer: What was, I'm guessing at 7 years old you didn't know much about epilepsy?

Participant: No I didn't

Interviewer: What about now, do you feel you're confident in your knowledge?

Participant: Oh yeah, yeah, definitely

Interviewer: What type of support did you get at that time?

Participant: None, just wasn't any around. Erm the hospital, the doctors at Hammersmith hospital where I was under said to my mum that I would have to go in an institution, because I would never be any good, and my mum came home and told my dad, he went over there and punched him the face and he said she's not, because my dad was erm, denied, he denied it, he was in denial all his life that I ever had anything like that so erm, he really saved my life to be truthful, because he denied, he wouldn't let them send me to homes, institutions because as well as you know if you go to an institution you're institutionalised, and become like the people you're with and you don't become your own person so I was just, but my mum was very strong, very strong character, and she wouldn't allow anybody to treat me any different, I mean she was blinking wonderful, she's like why I am now, without any knowledge of what she was doing at all, so if it wasn't for her, goodness where I'd be.

Interviewer: So it was the strength of your parents really that saved you from …?

Participant: Yes, yes, yeah.

Interviewer: How are you now, do you have regular seizures?

Participant: Well I don't have any grand mall, tonic-clonic seizures now, because they changed the name, erm, but I do have temporal lobe, I do have absences sometimes, my eyes go, there's over two hundred types of fits, some nobody would ever know you're having one and I get quite a lot of them.

Interviewer: Do you have any feeling before a seizure?

Participant: Not now, I used to but I don't now

Interviewer: How were they?

Participant: The things I had, if I had the tonic clonic seizures was my left arm, always my left arm, used to go straight, straighten out like that, and then when it reached there I would go into a fit.

Interviewer: Did it give you a chance to sit somewhere comfortable and …?

Participant: No, no, I didn't really know what was going on, it was too quick, it was too quick. I did stop it once, erm, because I was going out, my arm was reaching out like that and instimatically I got hold of my right arm grabbed my left arm and screamed no and pulled it back (laughs).

Interviewer: Is there anything that triggers your seizures?

Participant: Well they thought it might be periods, erm they thought it might be that, that made them worse anyway, helluva lot worse.

Interviewer: When you were on your periods?

Participant: There was no, they didn't know what triggered it, they didn't know what started it, well there is obviously everyone's got something wrong with their brain, a scar.

Interviewer: How do you feel after an epileptic seizure?

Participant: Well, I was, I had, I used to have about 14-15 a time, it used to come, it used to last, I never had a fit and got over it, I used to have about 14 over the course of about 2 days, day and night, so I wasn't really alive for about 3 or 4 days.

Interviewer: Was that because of pain?

Participant: No, no, because you're unconscious, and you use a helluva lot of energy so you're absolutely tired and I used to have thumping headaches, terrible headaches, you're sick and everything.

Interviewer: What about those around you, how were they when you have a seizure?

Participant: My parents were brilliant, my relations, all my family were wonderful, my school mates never took any notice of me, erm, I had wonderful school friends, still got them now, erm, the people in the dancing turned funny and they wanted my mum to take me away, erm, so I didn't go there after a while, it was too embarrassing

Interviewer: For them?

Participant: Well for me as well, everybody looking at you saying you're different, you know, well that sort of things so I didn't bother to go anymore.

Interviewer: What do you think people feel when they see you have a seizure, how do you think it makes them feel and how do you feel about that?

Participant: Well years ago, they didn't know how to cope with it and I've been in very precarious positions laying on the floor with people laying on top of me and sticking things in my mouth and oh, I had one in the school once when I was picking up one of my girls and there was a whole circle, it seemed like the school was all around me when I woke up, you know just gawping at me, you know staring, its people didn't understand in those days so it's totally different, totally different. And it was the ability to live with it years ago, that was harder than actually having fits.

Interviewer: Do you feel that you have or had any control over your seizures apart from that time you spoke about?

Participant: No

Interviewer: Not at all?

Participant: No

Interviewer: How did you begin to cope with being an epileptic, now when you were diagnosed you were only about 7 …?

Participant: It was only about 7 but erm …

Interviewer: When you were in your teens and you had to …?

Participant: Well it was very difficult, that was my worst period, and one of the drugs they gave me was an antidepressant, which as you know depresses you in the end, so erm, it was a very depressing time and I obviously felt as I was different, not as good as anybody else, I wouldn't go on the bus, I wouldn't go on the train, I wouldn't go out, I was very, like that. Conscious of the fact I could have a fit anytime and I didn't want to go out.

Interviewer: Was the medication not working as well as it should?

Participant: No, well it was, yeah it was when they stabilised, when they took me off the thing and put me on another medication, yeah it was stabilising it and I still just had the once month sort of 15 at a time, erm, it leaves an impact on your brain that you're different, erm …

Interviewer: Do you think that shaped how you turned out in the end?

Participant: No, because I fought against that in the end, I fought against that, because when I was working, I went on, I didn't know anything about the association till I was about

33, and I went to Greenford and there was a flower lady and she sold flowers on the pavement, and erm, there was this girl selling flags for epilepsy, and I went up to her and I said ‘ohh I haven’t seen that before’ she said ‘oh I go to a group’, this is the group I go to now, she said’ I go to a group’ she said’ you can come if you want’ but she was very, epilepsy must have been her second condition because she wasn’t very forward or very, she was frightened and shy and reserved and all that sort of thing, and so the flower lady who, who I knew because I used to go every week to buy my flowers, she used to say ‘aint it sad’ so I said ‘yeah but I expect she’ll be alright she’ll get on with it’ so she said, I said ‘ no I’ve got epilepsy, I’ve got two kids I go to work’ she stared at me, she stared at me and she said ‘but you don’t look like one’ so I said ‘how’s anybody with epilepsy supposed to look then?’ she said ‘but you don’t look like it, you’re normal’ I said ‘well everybody’s bloody normal,’ the swearing, I said ‘ well every body’s normal’ and that’s when it made me go bang, just hearing her say that, she’s a lovely lady and I still to, that’s when it really got me, and I thought no, I’m not going to allow people to say that about people, you know, and that’s when I started going to the branch.

Interviewer: And tried to make a difference?

Participant: Yeah and tried to make a difference, so and hopefully I did, well I have.

Interviewer: Do you think epilepsy changed your life?

Participant: Definitely, definitely, definitely because I never did the job I wanted to, I wasn’t allowed to.

Interviewer: What did you want to do?

Participant: I wanted to be nurse and I couldn’t because of the epilepsy but these days you can, it’s all that sort of thing, things that I wanted to do, I couldn’t do because you weren’t allowed to but now you are.

Interviewer: Has it affected your outlook on life?

Participant: Oh yes, yes, yes I’ve always thought it has affected my outlook on life because I’ve never looked down an anybody and I’ve never thought anybody is inferior or superior to myself, I’ve always thought of people as individuals and on the same level.

Interviewer: So it’s made you more understanding of everyone else?

Participant: Oh yeah, yes and it’s made me more understanding of, it annoys me really, one thing with the branch that annoys me is when people say ‘well nobody knows how to deal with me, nobody knows how to do it’ I say, ‘well do you know how to, how to deal with people who have got diabetes?’, ‘well no’, I say ‘well why should they know about you and you don’t about them’, you know it’s made me think along those terms and along that line and when I was, I don’t like to keep bringing this up but when my daughter was dying I thought to myself, ‘I’m sitting in this hospice and I’ve got no one, no one to talk to’ and yet you should, you should be able to find someone, and you should have someone to say you know, you can come talk to me.

Interviewer: And you think that's how it should be with epilepsy?

Participant: Yeah, yeah definitely, yeah.

Interviewer: Is there anything that you can't do now because of your epilepsy, before you couldn't get into the job you wanted to do, what about now?

Participant: Its only my own fault really, it's, it's basically anything I can't do now is typically, basically down to me because my mum, she gave me, no she implanted a fear of water in my brain, I had to have a bath with the door open, sing all the time and that sort of thing, I wasn't allowed to go into the sea unless I stood there facing them because she would frightened I would have a fit in the sea but I can't get over that, and about a few years ago I said to the kids, I said 'I got to get over this fear of water' so I went out to the swimming pool to learn to swim (laughs) oh, I lost my voice as soon as I saw the water, I did as soon as I saw the water but I did stick it and I did stuck it for 14 lessons and I just, I allowed myself to stick and I was so frightened, I was petrified but I managed to float. (Laughs) I can't swim, I can't swim still.

Interviewer: It takes a lot to float, when you're scared of water

Participant: (Laughs) oh dear well it was the only thing that bugged me, that I couldn't get over that.

Interviewer: Do you think there was a difference to how epilepsy was perceived when you were diagnosed and now?

Participant: Oh big, big difference. It's looked at now as something that happens to you, but in those days it was you're no good, they just put you in an institution and shut the door, and you should never be any good to man or society.

Interviewer: What do you think is the most difficult aspect of having epilepsy?

Participant: Living with it, the ability to understand it for yourself, that is the hardest thing to do.

Interviewer: What would you advise those who are newly diagnosed with epilepsy?

Participant: To take a good look at what they are not what the epilepsy is but what they are so that they can recognise that they're a person first and the person with a disability second and just get on with what they want to do within the limits, I mean not be silly, not be foolish and start driving if you have a fit every day, just to recognise that you are person, a person that can do this and that, do it, don't play and don't keep on thinking about what you can't do, just think what you can do.

Interviewer: What would make it easier for them to cope with epilepsy? Is it knowledge, support from family or support groups?

Participant: Well its knowledge, only if the knowledge is correct, because incorrect knowledge as you know, one word in the wrong place puts everything out of perspective, they've got to have the right knowledge at the right time, and you mustn't fill your brain with too much, obviously, you know just a gradual climbing up a ladder technique, but you got to do, you got to get an understanding of it, and also you've get have a real understanding of yourself, that's the most important thing. Doctors are the ones with all the medicine and all the cures; you are the person who's got to live with it so you've got to fight for yourself, live with you.

Interviewer: Do you have anything else to add that would be helpful to knowledge?

Participant: To those who are newly diagnosed is that the first fit could be the last and the last could be the first, so it doesn't mean to say that just because you have one you can have one for the rest of your life because it doesn't really mean that.

Interviewer: Thank you very much for your time. Really appreciate it.

Participant: That's ok.

Interviewer: The participant wanted to tell me about a friend of hers who had epilepsy after the interview.

Participant: Extremely wealthy and have a high status, I'll say that and they don't come from London, and because she was diagnosed, because she had epilepsy she had to lay in the back of the car on the floor when they took them out in case she had a fit and showed them up and let on to people that she had epilepsy. She was clever, she went to university, she's a teacher, she went to Oxford, she got a degree in music, she could play the piano like an angel, she's (inaudible) all she's done is being put down, always put down, never been encouraged, encouragement is the key to life. Everything, with children, doing their homework even needs encouragement; it's the key to life not putting people down all the time.

En of interview

13.4. UK Participant 4

UK Interview 4

Interviewer: How old are you?

Participant: 41

Interviewer: 41, and your marital status?

Participant: Married

Interviewer: How many years?

Participant: Err 14

Interviewer: Any children?

Participant: No

Interviewer: And what is your occupation?

Participant: I'm a warehouse manager for (a big supermarket)

Interviewer: How long have you had epilepsy?

Participant: Err since I was 13, so 28 years

Interviewer: Do you know other people with epilepsy?

Participant: Yes

Interviewer: You must do with the group?

Participant: Yeah

Interviewer: What were the circumstances around your diagnosis?

Participant: Err, I started having blank episodes when I was 13, err no family history of epilepsy so went to the doctors, sent to the hospital for tests, EEG, cat scans, diagnosed with absent seizures, had those for 3 years, on medication. Grew out of absent seizures, which is quite common for teenagers, and then unfortunately 7 years later tonic-clonic seizure returned. But thankfully the last one I had was 2000, so I've been seizure free for 12 years.

Interviewer: How did you feel when you were first diagnosed? I know this is going back a few years

Participant: It didn't really faze me, I didn't know anything about it, absent seizures were quite mild, I didn't know I was having them

Interviewer: What about when it came back?

Participant: When it came back it was more of a shock because completely out of the blue, as far as I'd been aware I was cured and that was epilepsy done with, err just one Sunday afternoon I was at home with my mum and dad and the next minute I know I'm in the back of an ambulance, so tonic-clonic seizures I was totally unconscious and when I came round in was in the ambulance on my way to the hospital, that sort of shocked and stunned. At 23, I was working, I was driving, suddenly find that I lose my driving license err, so I had to do that twice. So the impact of that, I wasn't so concerned having the seizures because by that stage I knew about epilepsy, more the impact of 'is it going come back a lot, how often am I going to have them' but it was more the impact on my life I was more concerned about. Err you know, working, driving, socialising it was more sort of you know, what sort of impact was it having on my life? I decided after a while 'it's not, bugger it', I thought 'I'm not going to let it control me, I might not be able to totally control it but I'm going to give a damn good go' and that's just been my philosophy.

Interviewer: What was your knowledge before?

Participant: Before diagnosis? Nothing

Interviewer: Nothing, what about now?

Participant: Quite extensive

Interviewer: Yeah?

Participant: Because of what I do as an accredited volunteer, I've had to go through a learning process, and it's a two day course we do it at head office and its 12 weeks' worth of distance learning, quite intensive, and we were signed off by the open college network so it is accredited. So that's why it's so valuable to the organisation, I can go out to speak to people with a level of knowledge and skill base, so now my knowledge is very good but beforehand it was nonexistent.

Interviewer: Do you think it makes it easier knowing you know quite a bit about epilepsy …

Participant: Yeah

Interviewer: …for yourself and others?

Participant: Yeah for myself because I understand 'ok I've been seizure free for quite a while' but I can understand, maybe not what's causing seizures, a bit of a medical understanding about it, but I'm more understanding of the possible impact and the treatments and things, so understanding that helps me a wee bit and enables me to help others and that's more important to me.

Interviewer: When it came back at the age of 23, the epilepsy, how did you start to cope with it, what did you feel you have to do?

Participant: I was more concerned about what impact it was going to have on me, I was working at, 20 miles from where I lived, err on the, I lived one side of Belfast and worked in the other, so it had an impact on travelling back and forward to work, it had an impact on just getting around in general, it had an impact on my social activities, I was a keen walker and rock climber, err so I thought 'oh can I climb when I'm having seizures?' and I decided 'yes', its changed how I approach my climbing, instead of going up the cliff face first, bringing the loop behind me and leading the climb, I would've gone second or third and the loop was already there, so in the likely event I had a seizure while I was climbing all I would've done is fall on the loop, I just made sure the group of people I climbed with were aware of the condition, and if they didn't want to climb with me they were perfectly free to say no and there was going to be no hard feelings so they were aware of the condition, they were aware of what to do in the event that I did have a seizure in the middle of (inaudible). So they were fine, no problem, you know give them some education about what they have to do, otherwise I just got on with it.

Interviewer: So you feel the way you coped with it was basically to just …

Participant: Get on with it

Interviewer: Make it part of your life, as it is part of your life?

Participant: You know I take a tablet in the morning, I take a tablet in the night and apart from that, that's generally how much I give it

Interviewer: What type of support did you get from your family and friends?

Participant: Family, you know wants to get over the initial shock first and the second time, the first time was probably harder for my mum and dad because no family history, no obvious injury, no brain injury or anything, nothing found, no lesions or anything so they thought 'what's caused it?' I think the normal parent reaction, 'was it something we did?' so it was probably harder for them to accept it first than it was for me. And then when it came back the second time all those feelings came back, maybe not just as strongly this time because they dealt with it first time, and the first time we had found out about the condition and we had found out about (epilepsy charity) and got some support, so we were a wee bit shocked when it came back but you know, certainly as far as support they gave me I couldn't fault it, you know, they understood I had to work through it, so if I wanted to try something or continue doing something there was never any, something they may have said you know 'should you be climbing?' it was never said to me but they probably said it to themselves, you know, I think they knew I was 23, if I felt I couldn't do it, I wouldn't have done it. It was just you know, being sensible with it, you know some of the doctors would've always said 'oh you know you can't do that anymore, you can't do that, you can't do that' I'm like 'why not?' you know as long as you're sensible, if you think you know how many seizures you have and how many you're having, and if you could sort of find out what's triggering your seizures, if anything like tiredness, anxiety, stress …

Interviewer: Do you think anything in particular triggers yours?

Participant: I don't, nothing that I would identify while I was having, nothing sort of stood out, it was one of those things that happened, so nothing stood out, you know, if I got really tired I was likely to have one, if I get really stressed, nothing sort of stood out when we sort of looked at it.

Interviewer: And you never felt like you could control it or anything?

Participant: You can take your medication and that but I wouldn't say you could control it because you just don't know when it's going to happen. But you just, you control it as much as you don't let it control you, I can't guarantee that taking a tablet will mean I won't have a seizure so I've no control over it coming back.

Interviewer: You're still on medication?

Participant: Hmm, a very low dose just to maintain it, mainly because if I want to come off my medication I have to give up my driving license for 6 months and I can't do that, I need my car for work, so I can't turn around and say, every year when I have my review with my doctor he says 'do you want to come off the tablets?' and I say 'no I can't'. If I was in a situation where I could do without my car I might think about it but taking a very low dose of the tablet, you know a tablet in the morning a tablet in the night and that's as much as I think about it.

Interviewer: That's alright then. Do you feel you have any feeling before a seizure?

Participant: No I never got, I never got anything, just bang. The only way I found out about a seizure was when I woke up on the carpet, (laughs) you know or wherever I had fallen.

Interviewer: How about after a seizure, how did you feel?

Participant: Tired and groggy, headache and that for a while, it was all taking me a while to sort of come round fully, a couple of hours before I was normal, whatever normal is (laughs)

Interviewer: What about those around you, how do you think they felt seeing you have a seizure?

Participant: I think there was only once when they actually saw me having a seizure

Interviewer: And who was this?

Participant: That's was my mum, it terrified her, and I, it wasn't that, the fact I was having a seizure she understood that, it was the fact the feeling of 'there's nothing I can do', it was her helplessness, because there was nothing she could do to stop it, all she could be was be there when I came round and that was more terrifying for her, 'there's my son having a seizure, possibly in pain' and there's not a damn thing she could do, you know to stop it.

Interviewer: How did that make you feel when you came round?

Participant: Ohh, well she was always just concerned that I was alright or one thing or another, when I immediately come round I was sort of, sort of too groggy and sort of out of it to sort of care, err it was that I knew mum was there and it was nice to know that your mum was there if you know what I mean, if you're not feeling well, that sort of a way, but apart from that you know it wasn't given a lot of thought.

Interviewer: Do you think you can tell people about your epilepsy?

Participant: Yeah I do all the time

Interviewer: You don't mind?

Participant: No, I couldn't be an accredited volunteer and not.

Interviewer: Do you think your life changed because you had epilepsy or may have gone a different way had you not had epilepsy?

Participant: Err it probably changed in what I wanted to do when I was a child, I wanted to join the RAF, err when I was diagnosed with epilepsy, you can't join the armed services, so that changed my career path, it's what I always wanted to do since I was a kid, so that was …

Interviewer: Did that affect you, was that hard to accept?

Participant: It was hard at first but then I thought 'ok, there's nothing I could about it, 'err what am I going to do now sort of thing' and even when I lost my, the seizures when they came back, I lost my license twice, it hasn't stopped, I've never not had a job, I've been quite lucky I've always managed to stay in a job, it's made it difficult sometimes with transport but I've always got round it. I've coped that way, I've just got on with it.

Interviewer: A sense of normality. Has it affected your outlook on life, has epilepsy affected your outlook on life?

Participant: I don't know whether it's made me, I wouldn't say its made me a worse person, in ways it probably made me a better person.

Interviewer: How so?

Participant: Because I probably have a better outlook on what I can and can't do, in limitations, because it wouldn't, if somebody told you know possibly you can and can't do certain things, you can't drive until you're seizure free, which may have a limitation on this and that and the other, you don't drive, if you live in a big city, if you live in London it's not such an issue, you've got the taxis, you've got the trains, you've got the DLR or whatever, but take that out of a big city and it can have a massive impact, you know the more rural you get, you don't have the trains, you don't have the buses so your feelings of isolation can be a lot more intense. I was in Belfast at the time, not a big city compared to London but the biggest city in northern Ireland so it was tough at times to get back an forward to work but between friends, family and work colleagues I always managed to get and from work, so …

Interviewer: How do you feel about your life now?

Participant: I wish I'd won the lottery but apart from that no (laughs) don't we all? No you know …

Interviewer: Do you think people treat you differently because they know you have epilepsy?

Participant: I hope not, I don't think so, if I was having more frequent seizures and people at work had seen me have a seizure you know they might look at me differently, it's no secret at work that I have the condition and talk about it openly.

Interviewer: You don't feel you're treated differently because of it?

Participant: No I don't feel because of it, so …

Interviewer: How is it perceived in your culture, I don't know whether your culture, you …?

Participant: It wouldn't be in the same as here, but its more, I guess more misunderstood, than anything else, people don't understand what epilepsy is and, I wouldn't say they were afraid of the condition because of their ignorance, but at times it can almost seem like that, I wouldn't say it's a cultural thing, it's more of a lack of understanding. That's probably the best way of putting it.

Interviewer: Do you think there's a big difference the way it's looked at in Belfast and London?

Participant: I don't think so, I think its' still you know, what you want to call it, the British culture as opposed to an ethnic culture whether its ethnic groups within the UK or in their own country or that, I think you know there's quite a significant amount of stigma attached but its enforced upon the sufferer and the sufferers family in the same way as in other cultures.

Interviewer: And what is the most difficult aspect of having epilepsy?

Participant: I suppose if you're having frequent seizures it can, I would if I was having a lot of seizures I think I would you know, the restrictions on your independence, whether that comes down to being tied to public transport through lack of car or whether it's being restricted in employment opportunities, social leisure activities you know, depending on the severity of your epilepsy, it would depend what the severity and what those restrictions are. If you're having a lot of tonic-clonic seizures it's obviously a lot more restricting than somebody who's having the occasional absent seizure.

Interviewer: And what advice would you have for those who are newly diagnosed?

Participant: Find out about the condition, think about what you can do with your new condition, don't let it stop you doing anything, you don't have to sit in the corner of a room and never go out again, yes depending on the frequency of your seizures and how severe they are, there may be restrictions on what you can and can't do but you should never let it, you know, let it stop you from trying, the only thing to stop you from trying is you and that's a personal choice, that's not because of the epilepsy, that's you saying 'I'm going to let the epilepsy control me'. If you're not comfortable going swimming on your own anymore but you enjoy swimming, well take somebody with you, don't go to the deep end of the pool stay in the shallow end of the pool, swim across rather than up and down, get out, still enjoy it, you know tell the life guard what your condition is and where you are, go and play football, you know, run around, cycle, if you still feel you can do on the occasions why should it stop you doing anything? I'm always a great believer in do what you can when you can.

Interviewer: And do you have anything to add, any other useful information for me or for anyone with epilepsy?

Participant: Just get on with your life as best as you can, there will always be at some stage where there will be restrictions and limitations on what you can do but I think it's you setting those limitations and not the condition, setting the limitations, that's how you should live it.

Interviewer: Thank you very much

Participant: No problem at all

Interviewer: It was a pleasure to talk to you

End of interview

13.5. UK Participant 5

UK Interview 5

Interviewer: How old are you?

Participant: 44

Interviewer: 44, what is your marital status?

Participant: Single

Interviewer: Do you have any children?

Participant: No

Interviewer: And what is your occupation?

Participant: Ohh, it's a good question, I don't know what to say to that really, because at the moment I'm not working.

Interviewer: You volunteer mostly?

Participant: Yeah I do at the moment and I'm not working

Interviewer: How long have you had epilepsy?

Participant: Erm, err 35 years, since I was 8 years old

Interviewer: Do you know other people with epilepsy?

Participant: Well, yes I do

Interviewer: Family and friends or to do with the charity?

Participant: Through charity and through, err, I've been in assessment centres so that way

Interviewer: What sort of assessment centres?

Participant: It's the, err, national centre for epilepsy, the child from St Peter where the point sends for assessment they don't know what to do basically, they start from scratch basically checking out what is the matter and how can we help, because I went to the neurologist and several times they said 'sorry we can't help you' and would a second opinion be advisable and then that way maybe we can go to an assessment centre, so I stayed there for about nearly 2 months, they sort of, the way that works is they start from scratch so they ignore what the neurologist had already found out, they start investigating from the beginning, which is quite good actually.

Interviewer: What were the circumstances of your diagnosis? This is a while ago I know.

Participant: Yeah it is but erm right, erm, it's sort of my father had died and that is most likely the trauma that triggered the seizure and I have to say my mother was very much on the ball in those days, because epilepsy was not much talked about and she had it read on the paper or magazine and saw on the television or somewhere she had seen about epilepsy and thought this might be it and then talked to the doctor and told 'look this had happened' and she had also seen absences and had this massive big seizure and was sort of unconscious, she couldn't wake me up one morning basically from that stage and so that was sort of the beginning of that diagnosis and that was then quite readily the diagnosed with epilepsy with all those EEGs and things available at the time.

Interviewer: Do you still have regular seizures now?

Participant: Now I've been 2 years without seizures

Interviewer: Congratulations.

Participant: So it's been a rocky road to that stage but yes (laughs)

Interviewer: You finally get there in the end

Participant: Exactly (laughs), precisely

Interviewer: How did start to cope with having epilepsy?

Participant: In the beginning I was only a child, 8 years old sort of, its denial, you know straight forward denial, and that's how sort of took it, I'm like there's nothing wrong and I just barge on with life, I suppose its derivative of that my whole life, its continued, it's not that I think that I have nothing wrong but I sort of thought its part of my life, I have seizures and continue with my life and that's about it, just part of, have a seizure continue with life, that's erm, because initially then my seizures were also simple partial seizures they were easy to disguise as well, which I did and then, not because I'm ashamed but because there was this fuss around you which was unnecessary but it happened.

Interviewer: Do you mean others that saw you having seizures?

Participant: Yeah

Interviewer: What did they do?

Participant: Well that's the thing they panic, they don't know what to do so you just end up you know covering yourself and I, mine was quite easy to sort of disguise so I did that. But erm, 2004 when I, my seizures sort of were greater and I lost consciousness and all that so there was no hiding basically (laughs), and I was anybody's after and that generalised the primary partial and so it's just relaxed in a way, although I was scared initially I just thought that happens and there's nothing I can do basically and it's frustrating, I cried out of frustration really because you get this sort of 'I can't do anything about this' and tried all the medications in the book but you just took your carpet burns and other sort of burns and sort of bruises that just went on and that's more or less it.

Interviewer: Going back to when people saw you having seizures how did that make you feel knowing how they looked at it?

Participant: I, you see that's the thing, I have no bad memories really and in London people helped me, in childhood obviously they don't know what they saw so children sort be like, 'what's happening?' they laughed and, but I don't think there's anything cruel about it as well because they don't know what they're watching when somebody's having a seizure. I don't have bad memories or traumatic memories of that either and later on as well, its more I have qualms about it, but that fuss they make arise, and I think, it's because the not knowing and they panic, and its calling the ambulance and you end up having to spend 4-5 hours in A&E which is unnecessary, nobody does anything with you anyway, you're just waiting for a registrar to discharge you and so it's that because all my life I was having the simple partial seizures, I saw everything that went on and I heard everything that went on, I just couldn't speak to tell them instructions (laughs) how to operate, which is extremely frustrating.

Interviewer: Where did you grow up, which country?

Participant: Finland

Interviewer: How long have you been in the UK?

Participant: Over 15 years

Interviewer: What type of support did you get from your family and friends when you were first diagnosed, I know you were quite young at the time?

Participant: Well, I've had no problems

Interviewer: Have they always supported you?

Participant: Yeah, I've had no problems

Interviewer: What do you think triggers your seizures?

Participant: I do think the biggest trigger have been stress and it's not the everyday stress you know these little things, but something a bit more substantial like what you carry constantly, spinal tap basically there, subconscious more like it, that sort of things, and I suppose also when you're not well, when your general health is poorly, and also when you've exerted yourself and you know coming to relaxed state, then you release that and you might have a seizure as well but erm they can be quite erratic sometimes and recently when I've been seizure free for a year or so I had a traumatic event and after I returned home I had two weeks of constant aura so we realised how easily they can return and so it seems that trauma in my life can bring it on.

Interviewer: Do you have feelings, you talked about aura, do you have any feelings before you have a seizure?

Participant: I do yeah, it's about just I don't know how, it's difficult to estimate how long before but I do get a sort of feeling, maybe 30 second- a minute before.

Interviewer: You have a chance to sit down?

Participant: I do, just that, you know, nothing more and I, if people are close by I might be able to, you know, say one word like 'seizure' and if they hear that fine and if they don't then I don't have a second chance to say that, so it's very brief and not everybody gets to hear that. I don't really know what to say, the thinking, by that time the thinking process has slowed down already and you know everything is, I can sort of feel myself going all the time and doing things. And while I had simple partial seizures I could feel as well, I could hold a hot cup of coffee in my hand and have a seizure in my left side, people were laughing and I found it hilarious too but the mind is a beautiful thing, to hold a hot cup of coffee there and have a seizure on the left side stare at the coffee 'don't drop' (laughs)

Interviewer: How do you feel after a seizure?

Participant: It depends again on the seizure type, the simple partial seizures I'm fine, good to go but the when I get unconscious and all that I get really tired, the muscles ache, quite tired.

Interviewer: How long does that last for?

Participant: The seizure itself, ok erm, that's difficult to say, 5-10 minutes you know starting from the seizure then going unconscious I'm not sure how long that's taking, 5 or 10 minutes then I might even fall asleep, it depends, I'm tired, really tired, muscle ache like you've been doing the boxing and running a marathon at the same time and erm, so I might take about 5-10 minutes but then that ache, then I would require rest really.

Interviewer: Do you feel you have any control over your seizures?

Participant: Sometimes I do, yeah, deep breathing sometimes help, maybe even postpone or not even have a seizure at all and but they are just a bit, and otherwise I don't know, those are probably the only ones, the bit of, and the fact that I also changed my life style you know taken out all the unnecessary rush and stress in a way (laughs). I don't need to run to the bus the next one is coming.

Interviewer: It's a good way of looking at it.

Participant: Yes.

Interviewer: Do you tell people about your epilepsy?

Participant: Not really, I mean, no its, its hmm, yeah I don't really no.

Interviewer: Is there a reason?

Participant: No, no not really, it's just that when do you drop into conversation, I mean I don't hide it, no, by no means, that's not the way.

Interviewer: You just don't make a big fuss?

Participant: Well no exactly, this is it, this is it, I mean if I need to yes I do I mean, now I don't feel the need even to say it because I don't have seizures but if, for example, if I did have still seizures I probably would say more but not really, no, because (inaudible).

Interviewer: Do you think your life has changed because of your epilepsy?

Participant: Well somewhat, yeah my initial plans were to be a Raleigh driver or a pilot so that was a bit of a disappointment, I had my eyes set on those roles so I don't know.

Interviewer: Do you think your life would have been very different if you didn't have epilepsy?

Participant: It might have been slightly, yeah, I don't know, there's so many ifs and buts, I don't know, who knows, because that was, the thing is its difficult to imagine life without it since I've had it since I was 8 years old.

Interviewer: It's been a long time, I can understand that completely.

Participant: It's like a, it's difficult to trust in life without that now. (Interview interrupted for a 2 minute silence at 11 on 11th November). It was a sort of adjustment also to the fact that when my seizures sort of ended, it was an adjustment to that as well you know, it was difficult to imagine life without it as well and its peculiar to say that because I didn't have them anymore because they had been a part of your life for 35 years and erm but is suppose …

Interviewer: You're learning to adjust without it.

Participant: Yeah and the thing is I suppose for me, it's easier than some other people I know, because I had not taken it, it was just on my stride basically, you know, I had a seizure just continue my life but you know erm still they weren't there anymore (laughs).

Interviewer: Do you still take medication?

Participant: I do, yeah

Interviewer: Do you think people look at you differently because of your epilepsy?

Participant: Hmm, no I don't think so, I, I'm sure some people do but I, very rarely I suppose.

Interviewer: So you don't notice people treating you differently or being funny with you because …?

Participant: No, no

Interviewer: How is epilepsy looked at in your culture? So if you think back in Holland, how is it looked at and how is it compared to the UK? You see any difference

Participant: Ohh, it's been a long time since I was there, erm, I don't really, I can't remember, difference? I don't know really any difference or any, I mean, it's difficult to say really because I've been 15 years over here you know.

Interviewer: So how do you think people look at it over here?

Participant: Hmm, (laughs) right, well I live in London where I've been very lucky and I, I haven't had no problems and I can only say very positive, and people just lack a bit of knowledge about that, erm but then again you can't really know everything about everything, and erm but it was erm, let's say 10 years ago it was very appalling that the medical staff didn't even know about epilepsy, when you went to family planning centres and stuff but erm I, I haven't had any problems and erm, yeah, how do they look at epilepsy here? Well I, let's put it this way in job applications situations there's still an issue, because it comes after an interview there might come the question 'can you do the job?' you've had an hour's interview, you've sent your application and they have actually invited for an interview, 'but can you do the job because you have epilepsy?' so hmm, I suppose just a whole lack of knowledge, I don't know what to say to that.

Interviewer: Do you think, what is the most difficult aspect of having epilepsy?

Participant: Difficult? Hmm, well I don't know, I, I suppose it is the erm, the not knowing when, where you're going to have the next seizure, the seizures themselves. Because you're not in control, because everybody wants to be control so I suppose that's probably it.

Interviewer: How do you see your life now? Where you are now in your life?

Participant: Its ok, it could be far worse, it could've been so much worse, and erm, obviously I'm disappointed in myself but that's a different story (laughs).

Interviewer: Why is that?

Participant: Well because I don't have a job and I haven't done the things that I should have.

Interviewer: Many people don't.

Participant: Yeah, well.

Interviewer: And they're perfectly fine. What advice would you have for someone who is newly diagnosed?

Participant: Well erm, I would erm, study the condition, I mean learn as much as someone can about the condition and take control of my own, and responsibility of my own condition because the consultant and GPs just don't have the time for your particular needs and then you would armed to ask the right questions when you go in to see the doctor and erm, also take care of, I mean you would know what to do with yourself as well.

Interviewer: You were in the Olympics this year, how did that go?

Participant: Yeah that was, that went well.

Interviewer: An achievement.

Participant: Well this is the thing I argued with Margaret as well, I said look ‘achievement is very subjective word, I mean one considers rising out of bed an achievement the other person doesn’t’ and so I don’t consider being in the Olympics an achievement and you know.

Interviewer: Well I heard you say it was once in a lifetime and I think you’re right because I still haven’t been to the Olympics.

Participant: Well this is, yeah, coming to London was once in a lifetime, I don’t think it’s going to be here again soon.

Interviewer: Not in our lifetime.

Participant: So that’s why I thought ‘better now, quickly’ because I don’t know if I can travel to Rio if I wanted to on my budget.

Interviewer: Thank you very much

Participant: No problem, I hope it helps

Interviewer: Thank you.

End of interview

13.6. UK Participant 6

UK Interview 6

Interviewer: How old are you?

Participant: 58

Interviewer: What is your marital status? Are you married?

Participant: I'm single

Interviewer: Single. Do you have any children?

Participant: No. I've got loads of nieces and nephews (laughs)

Interviewer: What do you do?

Participant: I am err, I'm medically retarded

Interviewer: Ok, how long have you had epilepsy?

Participant: Since I was 32, you can deduct from (laughs) I'll leave that to you

Interviewer: Ok, that's for me to work out now. Do you know other people with epilepsy? Friends and family

Participant: Well since I joined my west London group I've been very, very happy with them

Interviewer: When did you join them?

Participant: Ohh, well first of all erm, when I moved to Ealing which was when in 1970 oh sorry 1990 and erm then I left a while, they were so old and strange and I ran away.

Interviewer: Oh dear. But you've been happy with them since?

Participant: But I erm, it was with Dr Damien's encouragement and doctor and he erm, he enabled me to mix with people and mix with erm enabled me to mix with people again and so to go and mix with epilepsy friends and I decided to this wonderful thing by, by going back and Bernie and Annette welcomed me back with open arms so since then everything, they erm, they always welcome me back with open arms, especially Cindy and Robert you saw on the desk, yes, Cindy, you didn't see Robert yesterday, he, he's married to Cindy and he, she, they are wonderful, anything I ask of Robert he will do for me. He says 'hello' and he always teases and says 'you're my girlfriend' and you know 'you're my second wife' because we all come from the same district in Liverpool, Cindy and I, adjoining districts really and it was fantastic to find out.

Interviewer: How did you, what were the circumstances of your diagnosis with epilepsy, what happened?

Participant: Well after 3 erm, findings of whether I did have erm epilepsy erm, it came out that I did have epilepsy.

Interviewer: Did anything happen around that time?

Participant: Erm well, when my, when I found I was just at my sister's, I went down to my sister's one normal weekend, erm leaving here and looking forward to and erm my, my, my nephew when I was watching TV and he was, he, he just simply changed channels really and that started me off.

Interviewer: So nothing traumatic happened, nothing, no illnesses?

Participant: Nothing, well I have, I've got cerebral palsy as well, and I was born with it.

Interviewer: Did that have anything to do with it, having epilepsy as well, or do they not know?

Participant: My epilepsy is in the same spot as my …

Interviewer: Ok, how did you start to cope living with epilepsy?

Participant: Ohh, dreadfully at first, now I'm a bit more organised but err …

Interviewer: Why did it bother you so much, do you think?

Participant: I, it was new to me, it was, but erm I was working in the hospital, in, in chemical pathology and I knew that I said, I told them all that, erm I didn't want to know my own results, so that's why I went to a different hospital, you see and I didn't want to know my own results and so that's why.

Interviewer: It upset you that much that you had epilepsy?

Participant: No, no, no, I didn't want to, because I didn't want to specifically, I wanted to get, I wanted to let others in the laboratory know more about me and I wouldn't erm, if I did want to know I could always ask doctor Bull or whatever if I persist, if I worried about something I could always ask him but anyway what happened I got, I really worked hard but it was not the epilepsy that did me in it was the, it was the MP who cut me off, because when erm, it was the MP who said, who put down the hospital and I'll never forgive him for that because I would still have my job if, if erm it wasn't for him because although he wanted a bigger hospital and joined Westminster hospital as well, it, it is now Chelsea and Westminster erm it was a little family unit of St Stephens, we all knew each other, every, from the erm high to low and we all knew each other, you know and it was wonderful there, it was really, from mortician and upwards, you know and we all knew, it was, it was really, I could go on, but it was really and they gave me a chance. And erm, Leo gave me a chance erm Nick was erm my, my boss in, he was erm coping with erm with me, in the end he said you know, he said you are very good, you know, in the end.

Interviewer: Quite nice.

Participant: Yes

Interviewer: How did your family help you when you had epilepsy?

Participant: Ohh, well my, my, my as a child I was always, I felt really as if I was always being mollycoddled and this is why when I was, when I was, 1978, I was broke free from Brighton and came free up here, my sister, and my sister thought she had lost me and came searching for me, and I was in Brighton in, in, in Ladbroke Grove and she said 'well if this what you want well ok' and she erm, and she said 'fine but keep in, please keep in touch' I said ' I will, ok, please I just to be, my freedom' because everyone was, I wanted some space, you know and after explain that they were ok and Tom who was my social worker did erm, oh he was wonderful.

Interviewer: How are you now, do you still have seizures?

Participant: I have the occasional seizure if, if I am under stress and erm, but erm, and when I remember to take my tablets but I, but I do take my tablets, but the occasionally time I, I, I forget.

Interviewer: How did you begin to cope with having epilepsy?

Participant: Erm …

Interviewer: What helped you come to terms with it?

Participant: I said it's like everything else, I said it's going to be like my cerebral palsy, it's a hidden disease and so I thought its erm, my doctors, my GP and my specialist told me its err, it's a, you're going to have to take these tablets for life and erm I said 'fine' but didn't bother me, you know.

Interviewer: Do you have any feelings before you have a seizure?

Participant: I did have auras, I did have erm and I did have this taste in my mouth.

Interviewer: Ok, what sort of taste?

Participant: Erm, and I need chocolate, you know.

Interviewer: So you're craving for chocolate as well?

Participant: Yeah

Interviewer: What about after a seizure, how do you feel then?

Participant: Oh I feel I want to go, and, and, and oh I'm like a, just after a seizure?

Interviewer: Hmm

Participant: Oh I'm like a, Im like a, what's the saying, I'm like a like (inaudible), I'm like a, I'm like a, I'm so frustrated and so angry and so, I'm like a, with bull's head on, I can't get out.

Interviewer: Like you're trapped in your own head, or heavy head?

Participant: I'm like a kid with a bull's head on, I'm like a, oh what's the saying, there's a special saying, I'm like a, erm, erm, erm, there's I'm like a kid with a bull's head, its, I'm like a kid with a bulls head on.

Interviewer: What about those around you, how do they feel when they see you have a seizure?

Participant: Well luckily I only have erm, I've only had seizures in, in my own house.

Interviewer: So no one's seen you?

Participant: No one has seen me have fits outside.

Interviewer: Ok, does that make you feel better?

Participant: It does, yeah. Yes, but a friend of mine saw me have a fit outside, erm in, in the street and I was calling, I was calling her to call my friend (start coughing badly and asks for some water)

Interviewer: So your friend saw you having a seizure?

Participant: Have a fit and I was. I was trying to erm tell her to go and get Rob, my friend and erm that's the only time I feel so embarrassed, well not embarrassed but it was I always and apologise but it's a fact of life to go say I'm sorry afterwards but erm, and when, when I am in post

Interviewer: Seizure?

Participant: You know, post seizure they say 'oh you've just had a fit, haven't you?'

Interviewer: Do you think people treat you differently because you have seizures?

Participant: No, no, no, I don't want to be treated differently to anybody, you know

Interviewer: How are you now, how do you feel about life and …?

Participant: I feel wonderful

Interviewer: That's very good.

Participant: I go swimming, well I try to go swimming but I haven't been swimming because of my cold

Interviewer: What do you think is the most difficult thing about having epilepsy?

Participant: I think it's the erm, the attitude that people, that certain people have taken about it and we are trying to, trying to still, keep trying to at epilepsy and still trying to tell people that epilepsy is just like any other illness, its, it isn't a special illness it's just like any other illness.

Interviewer: What advice would you give others who are newly diagnosed, so if someone's been told …?

Participant: To come out clean about it, to come out and do as much as you can, don't be shy about it, don't, and come out join, join one of our, join us all and get to, get to join in all our activities and join epilepsy action.

Interviewer: How do you think people look at epilepsy in England?

Participant: Epilepsy in England, I think if they er, if they, it depends if erm, if they're aware of erm, if the specialists are aware of us, as they probably are, and if they tell us, the specialists tell us why we are then I think, then I think they're on the road to the path to us very well.

Interviewer: Thank you very much for talking to me and I really appreciate all your input.

Participant: Thank you

End of interview

13.7. UK Participant 7

UK Interview 7

Interviewer: How old are you?

Participant: 26

Interviewer: And what is your marital status?

Participant: Erm …

Interviewer: Single, married?

Participant: Partner, with partner

Interviewer: Ok that will do. Do you have any children?

Participant: No

Interviewer: And what is your occupation?

Participant: Erm I'm a technician, DT, technology technician

Interviewer: How long have you had epilepsy?

Participant: Erm since I was 15, 16

Interviewer: About 13 years ago

Participant: 10 years ago

Interviewer: My maths isn't what it used to be

Participant: (Laughs)

Interviewer: Do you other people with epilepsy?

Participant: Do I know any other people?

Interviewer: Yeah

Participant: I know a few people, yeah

Interviewer: Can you tell me the circumstances around your diagnosis, what happened around that time?

Participant: I just developed it

Interviewer: Nothing happened?

Participant: Nothing happened before hand, no.

Interviewer: How did you start to cope with it, that you had epilepsy?

Participant: Just dealt with it, it’s a fact of life, really (laughs)

Interviewer: Did you not find it hard that you had this condition?

Participant: Well a little bit, it’s just like anything that you, just like any illness, you just got to get on with it, deal with it.

Interviewer: How did your family and friends help you?

Participant: With erm just taking my pills regularly, because my memory’s not the best jut things like that and finding a job was difficult because my field of work, they don’t like it when you’re erm, well I can use heavy machinery and when I’ve got epilepsy as you probably know, but erm I have most of my seizures in the evening but according to them as long as you’ve got epilepsy you can’t use machinery and that’s the bottom line, its ridiculous.

Interviewer: Does that frustrate you?

Participant: Yeah, it does frustrate me a lot.

Interviewer: Did you feel that you sort of had to teach them about the condition and what you can and can’t do?

Participant: Hmm, yeah.

Interviewer: To reassure them or was it more for yourself?

Participant: To reassure them really, erm but I mean I did a university degree, what it’s a diploma and I had to do the same thing there and it was quite difficult because they weren’t knowledgeable enough about the disability to really realise and again it was, as far as they were concerned epilepsy, bottom line, can’t do anything.

Interviewer: Do you have any triggers for your seizures?

Participant: Yeah, stress is a very big one, err obviously not taking pills, err tiredness, erm dehydration and flashing lights as well but not in the normal sense, a lot of epileptics they have flashing lights but I have strobe lights affect but strobe lights don’t affect me, if it were to be a normal light like it would be lashing on and off, constant, constant ray then that would affect me.

Interviewer: Do you have any feelings before a seizure?

Participant: No aura, no.

Interviewer: Nothing at all?

Participant: No

Interviewer: How do you feel after a seizure?

Participant: Very tired, just like any other, any other person.

Interviewer: Do you have any aches?

Participant: Not that I've noticed, no.

Interviewer: How long does it take you to recover from the sleepiness after?

Participant: Oh that can depend hugely, erm, it can be anything, anything from a couple of minutes to a day.

Interviewer: What about those around you, if they see you having a seizure, how do they react, what do they do?

Participant: It depends who it is, but normally most of my friends they know I've got epilepsy and so they're not sort of scared or intimidated about it so they just know how to deal with it and know not to call an ambulance unless it's you know lots, lots of them intermittently.

Interviewer: How does it make you feel that they're almost accepting?

Participant: Oh it's good, I feel safe

Interviewer: Ok, do you feel you have any control over your seizures?

Participant: No

Interviewer: Do you feel happy to tell people about your epilepsy?

Participant: Generally, unless it's somebody I work for

Interviewer: Do you not declare at work that you have epilepsy?

Participant: No, I've got no other choice because otherwise I'd be permanently unemployed

Interviewer: Do you think epilepsy has changed your life?

Participant: Yeah

Interviewer: Or altered it?

Participant: Yes

Interviewer: How do you think your life would've been if you didn't have epilepsy?

Participant: I don't know it's hard to tell but …

Interviewer: Do you think it's restricted you in any way?

Participant: Yeah, quite, well I wouldn't have to tell an employer therefore I'd probably got a completely different job, you see the job I got at the moment is you know, otherwise I would've got into cabinet making and there is completely no restriction.

Interviewer: How do you see your life now? Do you feel it's on track with what you would've done anyway?

Participant: No

Interviewer: It's not?

Participant: I would've been a cabinet maker, or possibly set up my own business.

Interviewer: Why do you think epilepsy holds you back, what is it about epilepsy that holds you back, not to do what you want to do?

Participant: Well the fact that the seizures are not erm, what's the word when you don't know when they're coming?

Interviewer: Unpredictable?

Participant: When they're unpredictable, the fact that they're unpredictable

Interviewer: So you still have regular seizures, it's not controlled just yet?

Participant: Yeah it's not controlled

Interviewer: What's the most difficult aspect of having epilepsy?

Participant: That.

Interviewer: The fact that it's unpredictable?

Participant: Yeah.

Interviewer: Do you think people look at you different …?

Participant: Actually also on other aspects is that, other people, unless they understand it they just see it as an illnesses that's black and white as opposed to varying degrees of epilepsy, they just see it as epilepsy or no epilepsy.

Interviewer: So its lack of understanding, lack of knowledge?

Participant: Yeah very, yeah, huge lack.

Interviewer: Do you think people treat you differently because you have epilepsy?

Participant: Yeah

Interviewer: How would they look at you?

Participant: Erm, it’s mostly employers or people who are bound by insurance, insurance err what do you call it?

Interviewer: Companies?

Participant: Yeah, yeah I suppose so

Interviewer: Legal?

Participant: Yeah legal rights.

Interviewer: So do you think it’s more …?

Participant: They’ve got to be careful, yeah.

Interviewer: … Companies or its more people not knowing enough about it?

Participant: A bit of both I think.

Interviewer: What do you think would change this, what sort of …?

Participant: Knowledge, knowledge and understanding of both parties, people and erm insurance companies, because insurance companies need to be taught what the dangers are and the varying degrees of the disability.

Interviewer: What advice would you give others who are newly diagnosed with epilepsy?

Participant: It depends what age.

Interviewer: Any age, over the age of 18 that they know and are aware of their illness, their condition.

Participant: Be very careful about what degree you try and go into or what job you try and go into

Interviewer: Anything that you think I would find useful or you would want to advise others or you think is important?

Participant: Hmm, just I would advise people to tell others that have the disability or as many as they think comfortable that sort of around day to day

Interviewer: And you’re happy telling people, you don’t mind?

Participant: No I don’t mind.

Interviewer: Thank you very much for your input and good luck

End of Interview

13.8. UK Participant 8

UK Interview 8

Interviewer: How old are you?

Participant: 46

Interviewer: 46, and what is your marital status?

Participant: Single.

Interviewer: Any children?

Participant: No

Interviewer: And what do you do?

Participant: I'm a PA to a Finance Director.

Interviewer: How long have you had epilepsy?

Participant: About 7 years

Interviewer: 7 years, what were the circumstances surrounding your diagnosis, did anything happen around then?

Participant: Erm, I don't know, I just started erm, having … I don't know, I was in a pub in Kent having lunch and I ended up having I think a seizure, I think that was a year before that, I didn't do anything, I thought I just collapsed, I didn't know what happened, a year after I started being over whelmed, having emotional things, just getting emotionally overwhelmed, just this 30 seconds, 1 minute attacks, and it just continued and continued, this was all before I was diagnosed, then my family said 'enough is enough', because to be honest I've never had any health problems. I've never stayed in hospital, I've never …

Interviewer: So you were happy to ignore it?

Participant: Oh yes

Interviewer: Well thank God for your family. They persuaded you, what happened at the doctors?

Participant: And then after my sister kind of said 'that's it, get off your arse', I went to the doctor, erm she sent me to St Mary's initially, in Paddington, and she asked me erm, they did an MRI and it turned out I have a lesion right in the middle to do with memory, I think it's the one he talked about this morning, it's to do with memory and emotions, that's the one that is a lesion, its bigger than it should be and that's what causes the lesions. And since then it’s just been getting worse and worse and erm, I tend … like I said it started off with those kind of, I think it’s what the lady was talking about, Dr Jenny, she was talking, I think it started off with that then epileptic things, because I would sit there feeling totally overwhelmed, I would be sitting with you and you could say I’m from Iraq and I would say it’s that Kurd, that nice Kurd guy that used to be, he was a lovely guy, he was like all round and he would wear that special outfit, costume you guys wear, and he was all round and he was such a lovely guy, he used to make me that special tea which I hated (laughs), or the other Kurd who used to work with my dad in the office and he made me, you know I have nice fond memories that maybe I would emotionally, because we all left in a hurry you know, and I would get emotionally overwhelmed because it reminds me of nice memories or something would be a trigger or you tell me something, oh I don’t know something, and I would get this 30-40 seconds or a minute or two, and some people would know it and some people wouldn’t, but they started getting worse, they would be like, what I would call mini seizures, where I’m going to be vulgar excuse me, where I would urinate or the other side or once I was at a job interview I tidied up the papers and folded them and walked out or things like that or you know there isn’t anything in the house that hasn’t got a stain to be honest before I’ve done something, I carry a pair of knickers extra in my bag, so there’s always something, so they got worse and developed into full seizures, whether on the bus, on the street.

Interviewer: Are they controlled now or do you still have regular seizures?

Participant: No I continue having them.

Interviewer: Do you feel you have any control over them at all?

Participant: No

Interviewer: How much support did you get from family and friends?

Participant: Erm, my family being typical they just wanted it to go away, because that’s their attitude, make it go away, go and take something, go and do something and why does it happen? They kept on asking me the questions, ‘I don’t know, why are you asking me?’ and err, and me being typical me I just wanted to run away and avoid them, so I never stayed at home, I thought ‘well, if it happens and I’m on the street it’s safer’ (laughs).

Interviewer: At least my family won’t see me.

Participant: Yeah (laughs) and they won’t ask me the questions and you know the usual things and erm, but erm, and I suppose I didn’t want to recognise it if I’m honest, you know after 6-7 years this is the first thing I attended.

Interviewer: Have you found it helpful?

Participant: Very, very helpful if I’m honest, people kind of …

Interviewer: It’s a very nice atmosphere

Participant: Yeah, yeah, it's very lovely, yeah.

Interviewer: I wish it happened more because I think it would help a lot more people.

Participant: Hmm, yes

Interviewer: How did you feel when they first told you that you had epilepsy?

Participant: I was in shock, I was like 'no you're wrong, do something else, do another', and I changed hospitals, I went to another, Charring Cross, and the guy said, same diagnosis, I said 'no', 'well no' he said, he agreed but then I just found the medication I was given at St Mary's didn't work, didn't work and to be honest it started getting worse and worse, I think I was given the basic one right at the beginning, and it just got worse, and I suppose having a friend from school who I had known, I don't know for how many years, she had epilepsy, she had something here (point to the back of here head) at the back of her brain, err she was about 19-20, no she was about 22-23, in America and she started having seizures and they decided the best option was an operation, and she had the operation done but she continued having seizures for the rest of her life, to the extent that she ended up giving up her life and staying at home, doing nothing and erm, I thought 'I don't want to be like that' I mean she, she just became like on welfare, I don't want to do, I don't want to end up like that, that was my image in my head, so erm, and I kept on saying 'no I want, I want something that work, I want a solution' so erm, and to be honest I've always been the type to go out and find a solution, not the type who sits there and say 'yes, give me a pill'.

Interviewer: How did you find that you coped with it, to accept it, what did you feel that you had to do?

Participant: I suppose with this one because there isn't one thing, you know, you know like my mum and my sister whatever the fashion they did, you know if you had lipo they did it, if you this they did it, I was the other extreme, if you go you know, the other way, you know thank God, I never did any of that (laughs).

Interviewer: More individual you were then?

Participant: Yeah (laughs), you know, I would take supplements, I would do the what worked you know, I would do the fad things you know, I would do the alternatives more, I would you know, I would do the diet, change of diet things because I found they actually did work, but the acceptance is the hardest because 'well I've been doing things right because they work' because they did, and I'm thinking 'why did you give me this?' its like almost asking God, 'why did you give me this?' so the acceptance was the hardest part but then the seizures just started getting worse and worse and worse and worse, I did end up in neurology hospital and I've been there, Mr Shah, is, was lovely because he left, he retired and he was lovely, whatever I said he said 'try it, it's ok' (laughs), I think he probably needed a massage after me or something or drink or whisky to calm down.

Interviewer: You were stressing him out that much?

Participant: Yes (laughs) because like it doesn't work der, der, der, you know he never, he was, he was, he was a sweetheart, and I was like you know 'nothing happened, the MRIs doesn't say anything' he says 'no change' and I always go back and say 'well the drugs hasn't worked' (laughs) and I kept on getting off the drug and obviously that didn't help.

Interviewer: Why were you getting off the drugs?

Participant: I, I hated the fact that I was like so err, the side effects were too much but then I don't think I ever did it in a controlled manner which made the side effects worse.

Interviewer: Do you almost feel like that you wanted to take charge and not the pills?

Participant: Yes, yeah, absolutely, because I wanted to take charge of the problem because I am responsible, it's my body, so I kept off, he put up with me, bless him, until he retired, I didn't think he was that old.

Interviewer: Do you think there's anything that triggers your seizures?

Participant: Erm, tired, emotionless, too overwhelmed, sleeplessness, err, stress, kind of the emotional aspects of things.

Interviewer: Apart from, you said you feel overwhelmed, do you have any other symptoms of when a seizure is coming on?

Participant: Erm, sorry what …?

Interviewer: Do you have any feelings before you have a seizure? Some people talk about an aura, some people talk about …

Participant: The mini ones yes, not the full I never, it's like oh I'm talking to you the next thing I'm the floor I wouldn't know, but the mini ones, what I call the mini ones yes, yes I get, a get a feeling of déjà vu, ohh I know this, tera rera, you know it's a bit like that, feeling of I've known this experience or I know you somewhere or a feeling of I've had this experience, feeling of being very overwhelmed, and that's, I don't know whether I'm going to have the little, what I call the little one which I assume what that lady was talking about or the big one, and erm, and that's why I don't know what I'm going to do, like I said tidy up paper or erm, but I don't collapse on the floor, or I could just sit here …

Interviewer: So you're quite aware?

Participant: No, not conscious, no, I don't know

Interviewer: But you're awake, you don't know what you are doing but you are still doing things, you're functioning?

Participant: Yes, but I'm not, the next thing I know, I'm on the other side of the road, how I got to the other side of the road, I cannot tell you, or sometimes I could just sit here, I don't know, subconscious, I don't know, maybe you have a better idea of how the brain works than me, I mean once I was in somebody's house, and I, and I erm, I think I said I'm going to use your loo, and the loo was upstairs so I put on my coat and I said I'm going to use your loo and I went up the stairs and apparently I just came downstairs and walked off and the next thing I know is, she lives up the end of Green Lane, so there was a Tesco or something and the next thing I know standing outside Tesco, I was like 'how the hell did I get here?' but it must have been a good 5 minutes.

Interviewer: So how do you feel afterwards?

Participant: Oh a bit lost, I was like 'where am I?' you know, everyone knows Green Lane, I know what Green Lane's like. I can just describe it to you, I could say it starts with the famous Jewish, where the bagels are, and then you've got Finsbury football you know, Arsenal Football Club and you get on the bus and it goes all the way … you know, I can, I was stunned I was like, so to this day I still see the friend but she never, I don't, I think she's terrified so she hasn't invited me back to her house, I don't know.

Interviewer: Do you think that's how people feel when they see you have a seizure or an episode?

Participant: Yeah, they're scared

Interviewer: How does that make you feel?

Participant: Well I suppose it does make me feel a bit rejected in some ways but it's not my fault.

Interviewer: No, of course. Do you feel you have any control over the seizures?

Participant: No apart from controlling the physical aspect of making sure I sleep well, the emotionless …

Interviewer: Do you think that makes a difference?

Participant: I think so but I don't think I can guarantee it but it's a contributing factor.

Interviewer: Do you feel you are able to tell people about your epilepsy?

Participant: I'm getting better, where I do tell people, especially if I am spending more time with them, or if we're doing something together, if we're going, you know if we're going somewhere or something then yes, as a rule no, depends.

Interviewer: So you won't unless you have to?

Participant: Yes, but I do …

Interviewer: Do you think they treat you differently when they know you have epilepsy?

Participant: I think in the beginning some people do, I think after a while they do tend to forget about it, especially if nothing happens.

Interviewer: How do you think it's looked at generally, epilepsy?

Participant: I think with a little bit of confusion, because not a lot of people understand it, because a lot of people kind of see it as a different type of err, yeah they see it, they see it, I think because if you say you've got cancer or a heart condition or something, its advertised much better.

Interviewer: They know?

Participant: Yeah, with cancer 'oh you poor thing' or heart condition 'oh you can't exercise or you ate bad food or something' but with this it's like 'oh' and I suppose well Professor Sheldon said something, I suppose he's right, because he himself I don't know if it's true but he said 'we still don't know a lot about the brain', which is in a way true, he said 'you know there's still a lot to learn' (laughs).

Interviewer: A long way to go, definitely a long way to go.

Participant: I suppose the other annoying thing is if I do something odd people are like 'are you alright?' 'Will you sod off?' (Laughs) 'Yeah I'm fine, leave me alone' or why ask if I'm alright? Then it takes me a while to click and then it's like 'oh yeah, I'm fine' (laughs) it's like a, a bit of a …

Interviewer: You said your knowledge of epilepsy, because you had a friend who had epilepsy, was that your only source of knowledge before you were diagnosed yourself?

Participant: Yes

Interviewer: And how is your knowledge now, do you think?

Participant: I mean after today it got a lot better, yeah, prior to today it was all self-learnt.

Interviewer: So do you go after knowledge quite a bit?

Participant: I think when I suffer from something I go see (inaudible)

Interviewer: Ok

Participant: But then the other factor, another symptom of epilepsy is the energy level, that I found difficult, I still have a lot of energy, you know I grew up in London, I love London, I used to do a lot, and I now I barely make it to work, I barely make it home, maybe I do something at the weekend.

Interviewer: Do you think that's a side effect of your medication or the illness itself?

Participant: I don't know, could be old age (laughs) could a combination of all 3.

Interviewer: You've got a long way to go to call it old age.

Participant: I know but to be honest I don't know, I mean I used to come dancing here about 6-7 years ago about the same time and now if you tell me to go dancing I'll be like 'ok let's wait for it' you know to have the energy to do that,. You know an hour, no two hours after work, you don't finish work until 6, 6.30, but I still did it, it was nice, it was fun, it was great.

Interviewer: Something to look forward to do, to take up again maybe?

Participant: Yeah, I like to but now I haven't got you know, it's hard work.

Interviewer: What do you think the most difficult aspect of having epilepsy is?

Participant: I think the not knowing, and you don't, not knowing how to control it either, I mean if I know all I have to do is like, erm, with erm cancer it's like if you give up cigarettes, you know that will give you lung cancer, hey I'll give up cigarettes, I'll even give up coffee if they tell me that will help my epilepsy, well that's pushing it but I'll try, I'll give up something, or if you do, or it will lower the seizures, I mean I know what causes epilepsy, but it will lower the seizures, which would be nice to know what contributes and I think not knowing and also just having one, it's like 'what did just happen?'

Interviewer: So you still find it quite traumatic?

Participant: Yeah

Interviewer: What advice would you have for the newly diagnosed? Because you've had it for some years now, so what would you say to others?

Participant: Erm, I suppose take care of yourself, make yourself a priority, its hard work and get as much help as you can, its erm…

Interviewer: What sort of help do you mean?

Participant: Sorry?

Interviewer: What sort of help do you mean?

Participant: I suppose, yeah, don't be afraid to go out and keep asking, to be honest at the moment I've got Professor Cope at the neurology hospital and erm, I'm not afraid, well no I am not afraid, I have sent faxes and he has replied, I mean he's very sweet and it's ok to do that and people are afraid to do that, I think 'why? He is your doctor', so don't be afraid to do that, don't be afraid to go seeking help, because you have something serious and you need to find your answers.

Interviewer: Do you think it helps knowing that you do ask a lot of questions and you do take charge in a way?

Participant: Yeah, yes, because at the end of the day I mean they're not miracle workers, you can't assume they're going to sit there with a magic wand and here's your answer, that's what a lot of people expect, they hand the responsibility to their doctor and they're going to give them an answer, doctors don't do that, you know, I mean even if you spend the whole day with them, they can't tell you unless you open up and share. If you don't open and share and tell them, if you can't open and share and be honest, and if you don't ask, if you don’t say this is what happens and this is the change and these are the things and these are the der, der, der what can you do, they’re not going to be able to, just assume they’re miracle workers, and it’s not fair, they’re humans just like you and me, not any different and people hand them a lot of, because they’re too lazy to get off their arse and take responsibility for themselves so go out there and ask.

Interviewer: Do you know other people with epilepsy in your circle?

Participant: No, no. I mean unless, there must be somebody else at work, but nobody’s identified themselves.

Interviewer: Ok, well thank you very much for your contribution.

Participant: You’re welcome

Interviewer: And I wish you all the luck in the world

Participant: Thank you, you too.

End of interview

13.9. UK Participant 9

UK Interview 9

Interviewer: What is your age?

Participant: I'm 21

Interviewer: 21, what is your marital status? Are you single?

Participant: Single, yeah

Interviewer: Do you have any children?

Participant: No

Interviewer: And what do you do?

Participant: I'm a volunteer, I work in a playgroup for children 0-5 with special needs and illnesses and disabilities.

Interviewer: How long have you had epilepsy?

Participant: Since birth, for 21 years

Interviewer: Do you other people with epilepsy? Family, friends?

Participant: Only from my West London group.

Interviewer: Ok, how long have you been attending that?

Participant: Since I was 6

Interviewer: Do you like it?

Participant: I love it

Interviewer: Is it helpful?

Participant: Oh definitely

Interviewer: Do you get a lot support from them or more from your family do you think?

Participant: I think more support probably that place because I've grown with it as well, they might not have been born with it but as they've grown up with it, so anything I want to talk about which I don't want to talk to my mum about I've always got them to talk about.

Interviewer: And you trust them?

Participant: Oh yes definitely

Interviewer: What were the circumstances of your diagnosis did anything happen?

Participant: Erm, all scans my mum had, everything was fine, my mum's water broke at home and I think, even when my mum wanted to give birth I was struggling to breath I think, when we got to the hospital the heartbeat, when I stopped breathing like the machine monitor and I didn't have enough oxygen to the brain which left me with epilepsy and learning difficulties

Interviewer: So you know it's because of that?

Participant: Yes, yeah.

Interviewer: Obviously you were a baby when you had epilepsy but then you've grown up and at the age of probably around your teens you would have realised you had epilepsy, how did you start to cope with it and deal with epilepsy itself?

Participant: I think it was hard being the only one in the family because I literally have family from wales, family from Ireland, no one in the family have got it, I'm literally the only one in the family, so I thought, when I was younger I thought, 'am I the only one in the whole wide world with epilepsy?' because nobody else I know, no school friends, no family, nobody had it so I thought it was a rare condition, I'm never going to be able to talk to somebody about it, until my mum's work colleague and my mum found out one of her work colleagues also had epilepsy and she called me up talking to me because I was crying, struggling, I was just wishing like I was dead because I hated, I couldn't cope with it when I was younger.

Interviewer: And you found the support outside your family more helpful?

Participant: Yeah, very easy to talk to, and like my parents might not know everything about epilepsy because they haven't got it.

Interviewer: Do you still have regular seizure?

Participant: Oh yes.

Interviewer: On medication as well?

Participant: Yes

Interviewer: What do you think triggers your seizures?

Participant: Period, excitement, stress, if I'm ill and I've got a temperature, it varies.

Interviewer: Do you have any feelings before you have a seizure?

Participant: I used to, this year since April I've been fitting every month, I've had no warnings, but when I was 13 till 2010 I had warnings but this year not one warning until …

Interviewer: What about after your seizure, how do you feel then?

Participant: Tired, dizzy, confused, if I end up in hospital I literally won't, I'm an adult now, I literally won't let my mum leave the hospital, I'm literally so out of it, I feel like I'm more brain damaged than I was before I had a seizure.

Interviewer: So do you, how long does that take you to come out of?

Participant: Probably, I can't say, probably not till tomorrow I'll be back to normal.

Interviewer: So you need a full day at least

Participant: Yeah, not till the next day I'm back to my normal self, I might be a bit tired the next day and a bit like feeling weird but you wouldn't like, the day straight away I have a seizure I'm just not myself at all.

Interviewer: What about those around you when they see you have a seizure, what do they do?

Participant: It depends how old they are, I think if they're adults, my mums age, I think they're alright with me but if they're my age or maybe younger they get more upset as especially if they haven't witnessed anybody have a seizure, I think they probably get upset, I've noticed two of my friends have actually got upset thinking I'm dead or I'm going to die, because one minute I'm standing the next I'm on the floor and they think I'm dead having a heart attack or something and they always get like 'is she going to be alright, is she going to be alright, is she going to die?'.

Interviewer: How does that make you feel?

Participant: I think it was scary for me when I was little because I had no friends nobody like, if I got close to the they would be like 'back off, I don't want to be your friend, I'm scared of you' I think it really did upset me, but as I got older I'm getting used to it, even though I'm going to have it for the rest of my life. I'm not as bothered.

Interviewer: You've accepted it more?

Participant: Yeah.

Interviewer: Do you feel like you have any control over your seizures?

Participant: Not really.

Interviewer: How is your knowledge now with epilepsy?

Participant: It's better, I still ask my mum and dad some questions like 'how does it affect me, how, will my children have epilepsy because I've got it, will my children have learning difficulties because I've got it?' so there is stuff which I'm still scared about.

Interviewer: So you still don't feel you fully understand everything about it and you want to know more?

Participant: Yeah.

Interviewer: Do you tell people you have epilepsy?

Participant: Yes

Interviewer: You do, everyone or you don’t mind?

Participant: Whether I know them or not, I would rather just tell them in case I have a seizure that day or anything.

Interviewer: Do you think people look at you differently because you have epilepsy?

Participant: Yes, yeah I get stared at a lot in the street and I’m thinking ‘how do they know there’s something different about me?’ but I’m not sure if that’s my epilepsy or it’s my learning difficulties.

Interviewer: But you definitely feel that …?

Participant: Oh I get stared at every day.

Interviewer: How do you think people in general see epilepsy?

Participant: I don’t think a lot of people know about it, I think because I’m an adult now, everybody thinks I’m drunk or been drinking, that’s why I’m collapsed on the street, I don’t think they realise that just because somebody’s collapsed it doesn’t mean they’re always drunk or they’re on drugs or something like that, it can mean they could have an illness which people don’t understand because they’re just like walk past me and like, it might happen when I’m out so sometimes I have to go to hospital and a lot of people don’t even come up to me to check if I’m alright or ask ‘are you ok?’ they just walk past me thinking I’m one of those adults whose addicted to alcohol or something.

Interviewer: Do you think your age is working against you because you’re young, people …?

Participant: Yeah, I think if I was older or maybe even younger than I am now I think it might have been a different story.

Interviewer: What’s the hardest thing about epilepsy, bout having epilepsy?

Participant: Probably trying to live on your own, being able to drive, and be like other people my age or be like your friends, do the same things your friends can do.

Interviewer: What advice would you give other people who are newly diagnosed with epilepsy?

Participant: Don’t think the worst, think positive, whether you’ve got friends or not, I’ve grown up for over 21 years if you need a chat you’re welcome to give my number out and you can always contact me and we could always meet up and I help you grow up with it.

Interviewer: So you feel support from people who have the condition is the best.

Participant: Yeah, yeah.

Interviewer: Ok, do you have anything to add to help me or knowledge or …?

Participant: Not really, no.

Interviewer: Well thank you very much.

Participant: You’re welcome

Interviewer: Thank you

End of Interview

13.10. UK Participant 10

UK Interview 10

Interviewer: How old are you?

Participants: I'm 66

Interviewer: And what is your marital status?

Participants: I'm married

Interviewer: How old, how many years?

Participants: That's a difficult question, more than 30

Interviewer: Well I'm glad your wife isn't sitting next to you now. Do you have any children?

Participants: Yes

Interviewer: How many?

Participants: 2 children, a boy and a girl.

Interviewer: That's nice, grandchildren as well?

Participants: I haven't, not yet, no.

Interviewer: And what do you do?

Participants: I work for civil service, I suppose I'm a classed as a civil servant.

Interviewer: How long have you had epilepsy?

Participants: More than 50 years.

Interviewer: So you were quite young?

Participants: Yes, yes, I was 13

Interviewer: Ok.

Participants: 13, yes I say more than 50 years because I celebrated my 50th year, of having epilepsy.

Interviewer: More than 50 years?

Participants: More than 50 years, yes. If I was 13, that would be what, 53 years.

Interviewer: Yep, 53 years. What were the circumstances around your diagnosis, what happened around that time?

Participants: Oh very simply, meningitis. Meningitis leaving slight brain damage and that was, that was what it was, yes, so many people I know have a little brain damage so nothing else wrong with them.

Interviewer: Do you other people with epilepsy?

Participants: Yes

Interviewer: Family and friends?

Participants: When you say other people, large number.

Interviewer: Because of the organisation?

Participants: Yes.

Interviewer: How did you start to cope with it, because you were quite young, 13?

Participants: How did I cope with it is a good question? I think it's inbuilt that my parents like parents do, they try and overprotect, wrap you in cotton wool, which was just natural for parents and worry, but I just said 'look I'm going to do whatever I want to do' and I didn't realise it then but you got one life and you live it but as a teenager you don't think of things like that, and that's what I've done all through my life.

Interviewer: So you took control of your life?

Participants: Yes

Interviewer: What type of support did you get from your family and friends at the time?

Participants: When you say support, errm, people were just nice to me but I say nice to me but that's going back all those years, called the dark ages, there was so little known and so much has been, so much more has been found out since so, I mean at the time when I was 13, it was 'oh here you are take these tablets' which were phenobarbitone, and I think there were only two drugs going, phenobarbitone and that's it sort of thing, erm there was really no other help.

Interviewer: Did it help you though, the tablets that they gave you?

1. **Participants:** Not really, they just sent me to, well I suppose they did in a way but they just used to send me to sleep, which of course made coping with school etcetera very difficult.
2.

Interviewer: What do you think triggers your seizures? Do you still get seizures?

Participants: Yes, I've tried ever so hard to put down triggers but I know, I know this is to help the medical profession as well, temperature, which is you know a high temperature, if you're ill with flu cold or something, you get a high temperature, that does, that's quite common, that’s quite common with so many people, erm, and I, possibly lack of sleep, if I push things too far.

Interviewer: Do you have any feelings before a seizure?

Participants: Not really that I can put my finger on, no.

Interviewer: What about afterwards, how do you feel?

Participants: Well afterwards there’s a, I don’t know much about it at all, that, that’s quite common as well because all I want to do is just rest, I could just literally, just go to bed.

Interviewer: So you’re feeling quite tired after?

Participants: Yes

Interviewer: Sleepy?

Participants: It’s a question of , I think it’s what happens with most people, it’s difficult to describe because you have a seizure and sort of, there’s a mechanism in the brain it shuts things down to stop it, so this sort of shutting down erm, how can I put it, like as if you have interference on the television or something, if you turned it off that’s it, to get over it, you just need, you just need time, you just do nothing literally, whether its laying down or sitting to get back again.

Interviewer: What about those around you, has anyone seen you have a seizure?

Participants: Oh yes quite often.

Interviewer: What do they do?

Participants: I mean my children have been brought up with that fact, so they don’t worry at all, erm wife of course all my married life, so they’re quite aware of it and know what happens. Outside, colleagues at work you see, they know so nobody panics or anything like that.

Interviewer: How does it make you feel knowing that they’re happy and they’re ok with you having a seizure?

Participants: How does it make me feel? Erm, that in itself is difficult because, they don’t like me having seizures that’s, of course, it’s like anybody you don’t like to see them not 100%, erm, I think ‘oh dear’, you know’ I’ve had a seizure’ and that’s it I can’t do anything about it so I’ve got to pick myself up, brush myself down and get on with things, because I might not be here many years more.

Interviewer: Well hopefully you will be.

Participants: If I’m 66, you see what I mean?

Interviewer: You never, you know technology and science.

Participants: Oh well.

Interviewer: Do you feel that you have any control over your seizures?

Participants: No.

Interviewer: What your knowledge, before you were diagnosed, how was your knowledge of epilepsy?

Participants: Zero

Interviewer: What about after, now, obviously you would be an expert?

Participants: Well I know a lot more now, a tremendous amount more, I think I've been learning as, as the doctors have, erm one example being the MRI scan, which when I had epilepsy in the first place it didn't exist and I've seen various things come along, of course all the new drugs come along. I remember my first MRI scan, and the neurologist I was seeing at the time was looking at the pictures with and of course admitted, yes this is the first time they've seen these sorts of pictures of the brain, and they never been this far and they of course need to learn what it means.

Interviewer: So you learnt with them?

Participants: Yes

Interviewer: As they were learning, you were learning too.

Participants: Yes, it depends on the sort of neurologist doctor you have.

Interviewer: Did that help you deal with the condition, knowing you knew quite a lot?

Participants: Yes, I've never known you know too far into it, because there's no reason, erm because there's, there's, I've never let epilepsy take over my life, I've taken over the epilepsy.

Interviewer: So you feel in control?

Participants: Yes, completely, because a little while ago, it was somebody saying something to me, I said 'you know I am my own support, I'm the one, I support myself' the only time things go a bit wrong which I can't do anything about it is when I have a seizure, and that's it. For that period of time I'm not in control but every other, every other period of time I am, and I am responsible for myself, for what I do.

Interviewer: What do you think the most difficult aspect of having epilepsy is?

Participants: Difficult, one of the things, difficult, is, is perhaps the things that you can do or not supposed to do, now alright its dangerous for most people to drive, so you can't drive but other things like climbing ladders, you're not supposed to do that, well I do at home for painting the ceiling, well you just get on with it, if you restrict yourself too much you get neurotic about it.

Interviewer: I can imagine, and it takes over.

Participants: Yes and it has never has done you see, I don't let it.

Interviewer: Do you think your life changed with epilepsy? Or do you think it has geared a different way because of it?

Participants: It possibly has but then I was 13 as I've said and I've just done everything I wanted to do. I mean when I, when I first said 'I'm going away on holiday with a few friends and flying out' dear oh dear or dear, considered, considered what I shall I say, terrible but that's what you do, you just get on a plane and go somewhere.

Interviewer: That's a good way of looking at it.

Participants: Jobs you haven't asked me about.

Interviewer: I haven't asked you about jobs, no.

Participants: Well sorry; I'm taking over the interview you see.

Interviewer: No, it's ok, I don't mind, please tell me.

Participants: Well I was going to say that's never been a problem.

Interviewer: Having a job, or sticking to the job?

Participants: Well sticking to it, it's never been a, it's never been a problem, the epilepsy hasn't.

Interviewer: Why do you think it hasn't been a problem?

Participants: I've, I've, well one thing because of the availability of work, now people say 'oh dear, this that and the other with epilepsy' but there just aren't the jobs, they're not being turned down because of epilepsy for work it's just because you might get, not 2 or 3 people that apply for a job, you're probably getting 200-300 people and so if that person gets turned down well it's no surprise.

Interviewer: Have you always declared that you are epileptic?

Participants: Yes, ahh, epileptic no I'm not, I'm not epileptic, I never will be, I have epilepsy, I'm a person with epilepsy, because epileptic is a label, and the, in fact anyway epileptic refers to the type of seizure as opposed to the person. You will find I'm a person first.

Interviewer: Ok, well I apologise.

Participants: No, please don't.

Interviewer: I appreciate you explaining to me.

Participants: I could say quite simply I'm a person first, the epilepsy comes second, way down the line.

Interviewer: So you don't think it defines you at all?

Participants: No.

Interviewer: Ok, have you ever had problems at work then?

Participants: Problems? I've been lucky, I've been lucky; I can say no I haven't, but I know people who have.

Interviewer: Have you, do you feel comfortable telling people you have epilepsy?

Participants: Yes

Interviewer: And you mind anyone knowing that you have epilepsy?

Participants: No I don't

Interviewer: Do you, have you ever felt that they've treated you differently because..?

Participants: In size yes.

Interviewer: How?

Participants: Because I suppose they don't fully understand but then why should a person fully understand another person's complaint? Because there's lots and lots of complaints, disabilities I don't understand them all, so why should anybody fully understand about epilepsy?

Interviewer: Do you go out of your way to make people understand or to inform people or do you not feel the need?

Participants: Yes, because I mean I'm chairman of my local branch, Harrow branch in fact, and so that I think goes with being, being an obliged member that (inaudible), yes. Erm, where did I get to, oh yes I was saying I was a branch member, so the whole purpose is to tell people, inform people. We have, for instance, awareness days, and that's to inform people.

Interviewer: Just general public or people who know people with epilepsy?

Participants: General public because it, it, what it is mainly, we have displays in the local library or libraries because several people do this, so anybody coming along see these, I said days, they are days, over a two week period, and can see things, if they want any of our leaflets, they do, if they want to talk to somebody and in turn come to one of our meetings, ask questions.

Interviewer: Do you think that helps with the way people see epilepsy?

Participants: Oh it definitely helps them because its, people come along have either got epilepsy or they are related to shall we say, somebody with epilepsy and it's probably the first time in their life they've probably met somebody else knowingly, knowingly has got epilepsy so they can, gracious me.

Interviewer: Is it almost a relief for them?

Participants: Yes it is, its although they walk past somebody in the street without knowing it, because it's like if you have a heart condition, or so many conditions, you just can't see, so they come along and they meet people and they can talk to people and think 'oh thank goodness, yes'. It's a tremendous relief.

Interviewer: What is your advice to people who are newly diagnosed?

Participants: Advice? Now that is a very, very good question because, it depends how severe their epilepsy is. But the main thing is, I've always said live life to the full, because you've only got one life and it's such a pity if you don't, because that life then is gone and you've got, no matter who has got somebody, something to contribute, to the way we all live. Living life to the full as well, as far as I'm concerned being, being a male, I've always liked girlfriends, many girlfriends I've had, so that's probably the most difficult things, with a person with epilepsy going out with a girlfriend, doing the things that are perfectly normal but then explain to a girlfriend about epilepsy and usually they've been, been young girls as well at the time, they accepted it tremendously well.

Interviewer: So you haven't had issues with people accepting epilepsy?

Participants: I haven't, some people have.

Interviewer: What about other people, how would advise them how to cope, maybe to accept their condition, what would you, what do you think helps with that?

Participants: What helps? They've just to as it were grasp it themselves, they've just got to grasp it themselves, not feel sorry for themselves, even if they, I mean there's so many seizures, you don't always fall to the ground and hurt yourself, you could have other types of seizure but if somebody does have a seizure that you fall to the ground, all right that, that's a bit bad because you might wear glasses, you might break glasses or you might damage your clothes or something like that but don't feel sorry for yourself, because there's always somebody else worse off, erm, when if you watched the Olympic games, the Paralympics, all the people that have got sort of amputated limbs, I mean that's far worse, that is.

Interviewer: Any last words for us?

Participants: My last words are simply just keep taking the tablets, that's what I say to people, that's it.

Interviewer: Thank you very much for your time and wisdom, much, much appreciated.

End of interview

The participant wanted to add more to his interview so I started the recording again.

Participants: Yes, the, the only thing or perhaps things that sum up epilepsy, people say ‘ooh, by the way what is it, epilepsy’s what?’ and I say ‘as far as I’m concerned it’s just a nuisance, that’s it’ it’s a nuisance like so many things and I try to shrug my shoulders and get on with life, and if they want to know anymore, I say ‘oh well do you want to see how many stitches I’ve had?’ several years ago I hold quite a record, err, and those sorts of things. ’16 stitches down the back of my head, yeah, it’s a record in my area’ erm that’s not being involved in a car accident, just hitting, hitting the ground, and ‘oh, I didn’t want to know about that sort of thing’ I say ‘well, what do you want to know about?’ because epilepsy really is such a boring subject. so that sort of, I can, I can, add things as I think about them, as I go along, but perhaps that the way I approach, got to change slightly how you approach life.

Interviewer: Do you think if you explain to people, medically, what it is, they would be more willing to listen to what it is rather than the nitty gritty about the effects it has?

Participants: Medically I just say to them ‘yes it is just that’ erm like I mentioned before when we used to get on old televisions, the interference, well that’s like the brain, well there’s interference, there’s electricity up there and it just goes a little bit wrong, it’s ok again in a short time, it’s funny, sometimes it’s too simple for people, they want to know …

Interviewer: A bit more?

Participants: Yes, a bit more, then as we saw, there was a doctor this morning, a professor, was talking for an hour and a half, people don’t want to listen for an hour and a half.

Interviewer: No you’re right, you’re probably right, they’re not interested to listen for that long. I guess the detail is to make them understand, to satisfy their thirst.

Participants: I think people say, well I know what people have said to me as well, ‘‘oh, if you have a seizure’’ they usually call it fits but they’re seizures ‘‘if you do, what should I do?’’ they want to know what they should do, and so I can tell them according to the type of seizure again, because these days there are about 40 different ones, that’s only slight differences, you’ve really got seizures when you lose consciousness, fall over or you don’t completely lose consciousness, you’re standing up or you’re not fully aware of what’s happening around you, you’re just standing up, you could, I don’t know, you could do things you’re not aware of, but you don’t fall over, err but then again that’s sort of in the books shall we say?

Interviewer: Well thank you very much, again.

Participants: A pleasure talking to you

Interviewer: A pleasure talking to you, and very informative too.

End of interview

13.11. Kurdistan Participant 1

Kurdistan Interview 1 F 24

Interviewer: How old are you?

Participant: Now 23 to.., 20th December, 24 years.

Interviewer: 24?

Participant: 24, 88'.

Interviewer: Are you married?

Participant: Yes.

Interviewer: A long time?

Participant: A year.

Interviewer: You don't have children?

Participant: No.

Interviewer: Occupation, work?

Participant: I haven't been placed yet, but I work on projects.

Interviewer: What sort?

Participant: I go to the factory, if you know, gravel and sand, I work and waiting for my name to come up.

Interviewer: Is your work for short periods?

Participant: Yes.

Interviewer: Temporary? How long since you've had epilepsy?

Participant: Err, I was in year in year 6 (equivalent to second year of 'A' level) when I got it.

Interviewer: How long has it been?

Participant: What is year 6? I graduated 4 years ago, and 4 years for university, 8 years.

Interviewer: Do you know other people with epilepsy?

Participant: The same as mine?

Interviewer: Any time of epilepsy, the other types too.

Participant: Yes

Interviewer: Explain to me how it was when you first found out you had epilepsy.

Participant: Err, what feelings?

Interviewer: How was it for you, for example, when you found out?

Participant: At the beginning, to be honest I didn't even know the name, I didn't know it was like that. Like it affects your health so much, err, my mum, my mum wouldn't even tell me of course, she would talk to my aunt. Err, but it was normal for me.

Interviewer: How did she tell you?

Participant: Well, they wouldn't tell me, until they took me to the doctors then I found out it was epilepsy.

Interviewer: You mean you didn't know until then?

Participant: No, she wouldn't tell me, she didn't want to tell me. Of course I would see my mum crying, I didn't like it I would say 'God, is this illness I have so bad that's it's done?'

Interviewer: Did she cry at the doctors or at home?

Participant: I saw her crying with my aunt.

Interviewer: When she was talking about you?

Participant: Yes, she was talking about me, I didn't like it, and I would say 'ok, why is she crying? What is the difficulty in my illness?'

Interviewer: How did you feel when you first found out you had epilepsy?

Participant: When I found out it was epilepsy?

Interviewer: Yes

Participant: Well I feel it was from God, no bad feelings came about.

Interviewer: Even from the beginning it was normal for you?

Participant: It was normal, it was very normal, I know there's pain, my muscles tense up, its ok. But you know in my culture, like I told you, how we are. You mean me?

Interviewer: Hmm

Participant: It's fine for me.

Interviewer: It was normal for you even from the beginning?

Participant: Even from the beginning it's normal for me.

Interviewer: Tell me how it is in your culture, how is it seen in your culture?

Participant: Just that I don't like being like that in front of other people, I have that.

Interviewer: That's all?

Participant: That's all, like I told you, I don't like sympathetic eyes.

Interviewer: Just so people don't feel sorry for you?

Participant: Yes

Interviewer: It's not because of something else?

Participant: Nothing else, no, no, no

Interviewer: What was your knowledge on epilepsy before your own?

Participant: No knowledge, I knew, like Henna said we have it in our family, my cousins, err I know of course it's genetic, I don't know if it's genetic or not.. I asked my aunt, you know I said she's a doctor, she said this is a …

Interviewer: If you can explain it again because I hadn't recorded then

Participant: Ahh, how?

Interviewer: How you spoke to your cousin, how she explained to you?

Participant: I spoke to her, she said you have the substance in your brain, err, this substance when it's released more it causes your muscles to tense, like someone has to be next to you. Now sleeping on my own is bad for me, you understand? Even though it's very normal for me, but err when someone is close to you so when you tense up they can help you hold your eyes, because it affects you.

Interviewer: Why hold your eyes?

Participant: To close your eyes, of course eyes turn up.

Interviewer: Yes?

Participant: They told me because I don't see it, err and then my muscles tense up.

Interviewer: What is the benefit for closing your eyes?

Participant: The benefit, well I don't know the medical stuff just that my cousin told me, she said it's best if alone … because once I fell from the bed.

Interviewer: Yes

Participant: When I fell, it wasn't a nice thing, my mum was saying I can't even sleep on a bed, and I said 'mum, don't take it so serious', err, what was so whatsit, you know someone has to be next to you so when you force yourself and your muscles tense up when you're not aware, that person helps you, you don't whatsit, so you don't hurt yourself, there's no other harm.

Interviewer: Do you feel that with the closing of the eyes you wake up sooner, or...?

Participant: Well, me, that Doctor, if you know, when he said, when epilepsy comes there's no turning back, it's not like that a person can be wake you up. Before, my mum, before going to see the Doctor, before would wake me up often, I said 'mum, don't do that because when epilepsy comes you can't control it'. When during the epilepsy they close your eyes I don't know why, but this is the doctor's.

Interviewer: Did the doctor tell say your eyes should be closed?

Participant: Yes, put your hand over her eyes so they don't whatsit, maybe there's something in it, err the other thing, to hold the hands and legs so they don't fidget too much, so the person doesn't hurt themselves.

Interviewer: How comfortable are you that you have good knowledge on epilepsy?

Participant: Well, I'm comfortable, very, but err …

Interviewer: Do you feel you have complete information that you understand?

Participant: Once, even though you're talking, I read the whatsit information, it was English on the epitam, how much it affects the whatsit. One of those things was memory, of course it's like I forget a lot of things but err, sometimes they tell me something and I don't remember it, you understand? It's caused me that, the tablet.

Interviewer: Do you think that the forgetting is the cause of the tablets or the illness that you forget things?

Participant: It's caused by the tablets.

Interviewer: How long did you take the tablet for?

Participant: I'm still taking it, I'm still continuing.

Interviewer: How many years have you been taking it?

Participant: Err, well, it's not years, it's not been that long.

Interviewer: So before you didn't have memory problems, where you're forgetting things?

Participant: The whatsit, dipakin, my cousin told me it's bad for pregnancy. Its affects, I read it, with my husband the whatsit, we got a general medical book so we know, err, one of the things, it causes the baby to be disabled. So, I took precautions, err, this tablet, until I go to see a better doctor. They sent me to see this doctor, this doctor, gave me this epitam, he said in 100, dipakin, then he told me, even if you get pregnant you still have to take it, the tablet. You can’t be without tablets, so I don’t know, is it still the same where you are? In Europe?

Interviewer: I haven’t got information on medication and pregnancy, the doctor …

Participant: You still have to take it, continue with it, that person can’t be left without medication, even if it’s not controlled you have to take the dipakin.

Interviewer: You mean, even if it affects the baby? Did the doctor tell you if you’re on medication it will affect the baby?

Participant: It affects the baby, he said its 10% it affects the baby, before err, the epitam, he said 3%, before loxol was the tablet.

Interviewer: What?

Participant: Loxol. It was a tablet prescribed for me, err the whatsit, I read the information, my husband and I, it affects 1% of babies, in 1000 people it causes allergy in one person, I got affected, oh yeah.

Interviewer: Just your luck

Participant: In that 100, it was very good, the doctor said that even if you were well on the loxol, it would’ve been very good, because it doesn’t affect the patient or the baby that much, if you get pregnant, oh yeah.

Interviewer: And you can’t have that anymore?

Participant: No, no because it caused me such a bad allergy, my doctor, he said you have to go and have an injection quickly, err injection, my husband did it for me, and it was very strong too.

Interviewer: Injection against the allergy?

Participant: Against the allergy, it was that bad.

Interviewer: How did those around you help with when you were first told you had epilepsy?

Participant: A lot, in every way, psychologically, to make me comfortable

Interviewer: What did they do, for example, was it friends, relatives, who...?

Participant: No, mostly my mum and brother

Interviewer: Your mum and brother?

Participant: Yes

Interviewer: What did they do?

Participant: After that my husband

Interviewer: How did they help you, how did they have your back?

Participant: Like I told you, psychologically, like there are some heavy duty jobs, some you know, like a whatsit child they spoil them, I had that at home before I got married, of course my husband is like that too for sure, err in thingy, do you mean during a seizure or at the beginning?

Interviewer: That time when they told you you had epilepsy.

Participant: There was my cousin, of course I sat with her a lot, sometimes I would sit with her for a day, poor thing it was her job as well, she sat down and said that it was a very normal thing, I don't know if it was to help me psychologically, whether she was being kind to me, she said it was very normal, she said that you may not even need your tablets within 2 years, even if you leave it its ok, it something very, you know she helped me psychologically, err just like that my family also said so 'what is epilepsy? It's normal', because I don't see it they see me, they said it was normal.

Interviewer: So you were comfortable when they took it normally?

Participant: For sure, for me as I told you, it's very normal for me, the illness is no problem, I have no problems with the illness.

Interviewer: I wish you good health. How is your health now, do you get it often or no?

Participant: No, at the moment, this previous month no.

Interviewer: How long since you got it?

Participant: Err, what I told to you the dipakin, of course the dipakin is like the revoltin you get addicted to it, so if you know when it gets into your blood it takes a long time for it to come out. For that time it wasn't in my blood anymore, it came back, when it finished then I started having epilepsy again, I said, I got it a few times after one another.

Interviewer: When was this, how many months ago?

Participant: Err, well our girl wasn't dead then, it before, before that, so, I was lying down on a bed, my mum was with me, 2-3 times one after the other, as I said they increased my tablet dose, he said you can't take more than that, so later I reduced my medication myself. So when I still got it, it was out of desperation I was prescribed revoltin, because revoltin is not prescribed until the last resort for the patient.

Interviewer: Because it's very strong or because of the effects?

Participant: It's very strong, 2m, one tablet, it's a very small tablet, it affects you, it gets you better, you understand? After the dipakin wasn't in my blood anymore, then from then I haven't got seizures.

Interviewer: Good. What are you feeling before you have a seizure? Do you feel anything before?

Participant: How?

Interviewer: For example when you sleep that's when you seizure, right?

Participant: Yes

Interviewer: That night before you have a seizure do you have any feelings, headaches?

Participant: Before? No

Interviewer: You have no feelings

Participant: But, err with every single one I get a bit down, of course when I get it, sometimes I even hear my own voice moaning, you moan with it.

Interviewer: Yes

Participant: Err, like you say, it's like you're coming out of a deep well, it's like that, bad dreams and depressing

Interviewer: Before?

Participant: Even after, after and before. Err, before I get like that I get, erm, a headache, I get a bit down and then like you say having a bad dream, then, it's like for me I don't know how others around me see it.

Interviewer: Have they told you how they see you before?

Participant: Well, err, my mum and them have not told me, so I don't know how.

Interviewer: So you don't worry?

Participant: Ah, of course I told my mum, I was trying to make her feel better, I would tell my mum 'its ok, don't worry about it', that time I really pushed my husband, he told me how it was. He said at that time you, my tongue had an ulcer at that time, it wasn't an ulcer, one, I went to the doctor, err, I was going to the dentist anyway, I thought maybe I can do the top tooth whatsit, like shave it down a bit because in that time you pressure yourself, but now my husband takes lots of tissue and put it in my mouth so I don't bite, of course he was very good to me. It was lately that he discovered how to do it, err, then you have to hold on, I don't know how, he says you froth at the mouth, but, he says someone, the worse ones are when they wet themselves, but thank God I don't have that, but they tell me I only froth at the mouth, I don't know. And that your eyes turn up before.

Interviewer: Explain to me how, for example, if something bad happens, hear some bad news to affect you so that you have a seizure that night?

Participant: But it couldn’t be controlled at that time, when I was taking the dipakin my epilepsy were not controlled, err, and as I said there were the harmful effects, err, before that the whatsit, as I say the bad news was that the seizures were not controlled, err, like I say my worry was, I was worrying about my studying, I couldn’t study when I was at University in level 2 then I got it twice, one after the other, like that, then now that it’s controlled I don’t know when it’s happening, before I don’t know.

Interviewer: So because your seizures are controlled by the tablet, everyday things don’t affect you?

Participant: No, now when my niece passed away I was really stressed and it didn’t affect me.

Interviewer: How are you after a seizure?

Participant: Well, if I say well I’m not well, one of the things my body is stiff, my muscles properly.

Interviewer: For how long?

Participant: My muscles properly, even my throat muscles, properly, maybe like that, like I’m telling you, you might suffocate, someone has to be with you, it just has that.

Interviewer: Your body gets stiff, for how long?

Participant: My body muscle, my stomach, in that time I feel nauseous because my muscles, my stomach, all my body muscle

Interviewer: After a seizure?

Participant: After seizures things like that happen.

Interviewer: For how many days or hours?

Participant: For the first day I’m very whatsit, one of the things is psychologically I like a gathering, I feel down

Interviewer: You want to be around people?

Participant: A lot of people to be around me, feeling down and that stuff come with it.

Interviewer: What do those people around you do when you have a seizure?

Participant: What do they do?

Interviewer: Those around you, what do they do?

Participant: Well my husband is very calm, it’s normal for him, because he’s read a lot on it, it’s normal for him, it’s not a problem for him, but the worst is, it affects my mum a lot, it gets her very upset, like when I see her upset crying, I don't like it, even I don't like it when she's beside me. Of course they're all upset by it but my mum first.

Interviewer: How do those around you see you? Apart from your mum and your husband, has anyone else seen you?

Participant: Yes

Interviewer: How do you think they feel when they see you like that?

Participant: I don't know, but err, they try and make me feel better, not make it worse for me.

Interviewer: But how do you see it? How do those who see you feel? Do they feel sorry for you, does it upset them?

Participant: I see them, it's that of course, they feel sympathy, they have that, I'm not saying sympathy is bad, but it's not like an able person, I don't like that.

Interviewer: You don't want any sympathy at that time?

Participant: No, for example, you know the sympathy, some people want to call it shame, like, like shame, for example, empathy, empathy is different than that person saying 'oh God, have you not seen it?' you may not have mixed too much 'oh poor thing see how unfortunate she is?' some things, just in case it's looked at, they have that in them, they don't visit me, there's nothing like that.

Interviewer: Do you feel you have any control over the seizures?

Participant: You mean how?

Interviewer: Can you control it, for example not to seizure one night?

Participant: Well, if you take medication it doesn't affect you.

Interviewer: Do you feel that with your own strength, psychologically you can make yourself not seizure?

Participant: No

Interviewer: How did you begin to accept that you have epilepsy?

Participant: How?

Interviewer: For example, accept the illness, accept the illness is part of you.

Participant: It's very normal

Interviewer: How did you begin that, was it understanding the information on the illness or the understanding of your friends and family?

Participant: For sure it's understanding from those closest to you, secondly I'm very comfortable with it, it's fine for me.

Interviewer: Do you feel you can tell people that you have epilepsy?

Participant: No, I don't like that.

Interviewer: Why?

Participant: As I said, if someone isn't empathetic then I don't like it.

Interviewer: How has your life changed because of epilepsy?

Participant: It's changed, of course it's affected me, but not like that, I say

Interviewer: How has it affected you? What are the effects?

Participant: Just those things, like, my sister in law says don't stress you're unwell, like that you know? Otherwise like affects, no, just if I get ill and have to be bed bound otherwise it doesn't have any affects.

Interviewer: So it hasn't held you back, for example, to do something in your life or decide something, work?

Participant: No, no.

Interviewer: When it was clear you had epilepsy, did this affect how you see life?

Participant: You don't mean suicide or …?

Interviewer: No, your views, for example, move yourself away from something, or not wanting to mix with others too much …?

Participant: Yes, staying over, I'm like that, say now, before my sister in law, I don't like it still, me for myself even before I like visiting other people but to stay over at other places I don't like it.

Interviewer: So you don't stay over because..?

Participant: Well, you know, not because of that, it's one of the main things but I don't like it myself either to stay over at night.

Interviewer: But that has affected it?

Participant: Even if I stay over it's for of my husband.

Interviewer: Has there been any other difference to your attitude? On your attitude to life?

Participant: You mean how?

Interviewer: For example, you had epilepsy and you got married and you are happy, was there any time you thought you shouldn't do this because you have epilepsy, or to work?

Participant: You mean not get married because of that?

Interviewer: I mean has it affected your decisions for your life?

Participant: No, no.

Interviewer: Do you feel that epilepsy has changed your life?

Participant: Yes, one of those is I got closer to God.

Interviewer: How would people see you if they knew you had epilepsy? How would they treat you?

Participant: I told you before how it was, for sure, now there is bread making if you know, me, even before I didn't do it before I knew I had epilepsy, my mum hasn't made me do it, but since my in-laws have found out I don't do those chores.

Interviewer: In your culture, which is also mine, how is epilepsy seen? For example, if it's spoken about outside or with the relatives, if they don't know you have it?

Participant: I told you, with a shameful eye or sympathy. They find a fault in that person.

Interviewer: What sort of fault, do they look at you with less, see it as a disability?

Participant: Disability.

Interviewer: Disability? Mentally or their views or understanding?

Participant: For me. Of course, err not for me, until now no one, my in-laws don't know, I don't know if someone else knows but hasn't said anything, err my in-laws I don't mean their family, their other family, we were in a funeral they were talking about a girl, they said that girl isn't mentally well, I heard from someone.

Interviewer: You mean they were talking about you?

Participant: No. no, not me.

Interviewer: Someone else?

Participant: Someone else, they were saying she's not mentally well don't talk to her too much, I thought it was strange, she was a normal girl, very whatsit, 'I think she's not mentally well'. One day the husband of the person saying that, whatsit, said 'poor thing they have got whatsit,' like their traditional ways they cover their head with a black cloth, 'poor thing is like that' when he said the things I had all of them, and I said 'is this what is made mentally?'(Laughs).

Interviewer: You mean that's how they saw it?

Participant: Yes

Interviewer: Not get close to someone because they have epilepsy?

Participant: Yes, of course when I saw this I became, I thought 'poor thing what's happened, poor girl is normal, good chitchat, to be said this about her?'

Interviewer: Just because she has epilepsy?

Participant: Just because of that

Interviewer: What's the most difficult thing for you because you have epilepsy? The most difficult effect on your life?

Participant: You mean how?

Interviewer: I mean for example, your life decisions, way of life, making a family?

Participant: It hasn't caused any difficulties

Interviewer: Nothing?

Participant: Nothing, no

Interviewer: For those who are being told they have epilepsy, how would you advise them? How would you make them understand that …?

Participant: Well, if I sat down myself I would do, I would tell them that because someone has an illness you don't need to be upset, that person might not even be upset, not everyone is like that, be upset, if someone understands they won't be upset.

Interviewer: You mean understanding the illness?

Participant: Its understanding.

Interviewer: The illness or life in general?

Participant: In general, this is the way (life), in your was you come across everything.

Interviewer: Yes you're right. Is there anything you want to talk about that I haven't asked you, you feel is important for me to know about epilepsy?

Participant: How?

Interviewer: Like there may be something important for someone who has epilepsy?

Participant: Well for me, they should be truthful with the patient rather than hide the illness.

Interviewer: With the patient?

Participant: Yes

Interviewer: What are you hopes, for your future?

Participant: Well I have many hopes, I'm not without hope.

Interviewer: Thank you very much, I hope you every success for your future

Participant: Thank you.

End of Interview

13.12. Kurdistan Participant 2

Kurdistan Interview 2 M

Interviewer: How old are you?

Participant: Now ’82, around 30 years

Interviewer: Do you have a wife?

Participant: Wife, no.

Interviewer: You haven’t got any children?

Participant: No

Interviewer: What do you do?

Participant: Teacher

Interviewer: Teacher, what sort of teacher?

Participant: High school teacher, Kurdish language.

Interviewer: How many years have you been a teacher?

Participant: Around 4 years

Interviewer: How many years have you had epilepsy?

Participant: Well as long as I can remember I’ve had epilepsy

Interviewer: You don’t know how old you were?

Participant: I think I got it around the age of 11

Interviewer: 11 years, you don’t know how you got it?

Participant: Well I don’t remember properly, but I think I got it through fear or when I was younger I may have fallen, I feel that my head may have got hurt and I got this.

Interviewer: Do you know other people with epilepsy?

Participant: With family yes, but outside no, outside, outside I’ve seen it but to know them no I’ve not known them, outside I’ve seen other people fall like me like that.

Interviewer: Do you remember when they told you you had epilepsy? When they took you to the doctors and said you have epilepsy?

Participant: Well they would tell me but I didn't know that it was like that or if it was just stress that caused me to be like that

Interviewer: I know you were young then but how did you feel when they told you this was the condition?

Participant: Well, because I was young I didn't really pay attention to it, I didn't know it was for my future, I thought I would get better, I thought epilepsy was that you get it for a month or two months or a year or two years then you get better, but I didn't know this was going to be with you forever, when you get older the stress is more than when you're younger.

Interviewer: How is the stress for you now?

Participant: Well, now the stress is a lot more, when younger you don't worry about things much but when you grow up you see these things, or you hear it from people 'you got like that' it just bothers me.

Interviewer: So you don't remember when you get like that?

Participant: I don't get like that until people tell me.

Interviewer: So you don't know what's happened?

Participant: I feel a dizziness come over my brain, I say I'm not going to fall, nothing's going to happen, the next thing I wake up in other people's hand.

Interviewer: Outside or at home?

Participant: Everywhere, it doesn't matter, when it comes it comes wherever I am, if I'm on water, even if I fall I won't feel it until I die.

Interviewer: Now, you probably didn't have knowledge because you were young when they told you had epilepsy, but how is your knowledge now?

Participant: Well, my knowledge is this, there's a vein in my head, it's come out in tests, they say a vein in my head is not getting a lot of blood, they say this is causing, when there's not enough blood getting to my brain, like the vein is blocked, when it doesn't go you're going to fall, when you get like that.

Interviewer: Is there a cure?

Participant: Well, the cure is medication and I can't stress too much.

Interviewer: Do you feel that you have any control so that you don't have a seizure?

Participant: Well, sometimes yes but sometimes it's stronger over me.

Interviewer: How can you control it?

Participant: Well I watch something, or read something or speak to someone or feel that when two people are talking to you, I will listen to one and pay attention to the other, so when I feel I'm starting to get like that I make myself busy with something else.

Interviewer: So you get yourself away from it?

Participant: Sometimes yes, but sometimes I can't, it hits me straight away.

Interviewer: Family and friends, how have they helped you so you can live with this and accept it?

Participant: Well they've helped me as much as they could've but if it's not in their power, what can they do?

Interviewer: How do they help?

Participant: They've tried so that I don't stress, whatever I've liked, if they could have done it they've done it, they've helped me a lot, like that.

Interviewer: What do you do, do you take medication?

Participant: I take medication, I take medication and sometimes I have to watch myself.

Interviewer: When did you last have a seizure?

Participant: Well today.

Interviewer: Today?

Participant: Yes

Interviewer: How often do you have seizures?

Participant: Well, sometimes once a month, or once every two months, or 6-7 times in a month, depending on stress and thinking.

Interviewer: What happened today when you had a seizure?

Participant: Well…

Interviewer: Anything in particular happen?

Participant: Like I say, when I stress and think, it's like that, it hits me.

Interviewer: Nothing in particular happen when you got like that today?

Participant: Well at work I had a bit of a stress it affected me today.

Interviewer: You said before you have a seizure, your brain is a bit mixed up …

Participant: Yes it mixes up and things are very strange when, I don't know what to say, I can't explain it like a thinking process but I understand it, when I sometimes get like that I feel I’m going to fall, and then when I wake up, I realise it when people are waking me up and putting water over my mouth.

Interviewer: How long does it last?

Participant: Well, people say 3 minutes, 4 minutes.

Interviewer: Just that much?

Participant: Yes, but I don’t know.

Interviewer: Have you hurt yourself at that time, do you always fall to the floor?

Participant: Yes, I get hurt, yes.

Interviewer: How do you feel after?

Participant: Afterwards I go in shock, every time after it’s happened to me, my head is about to explode, now my head is about to explode, I like a lot of sweet stuff and soft foods, after I get like that.

Interviewer: What about those around you when you wake, how do you feel?

Participant: If I know them, it’s fine but if I don’t know them I get a bit embarrassed and bothers me.

Interviewer: Why does it bother you?

Participant: It’s just I feel like if they see me out or somewhere, they say ‘it was that boy who had epilepsy’ or ‘the one that got ill or the one that fell on his mouth’.

Interviewer: Why does it bother you?

Participant: It’s just nice, it’s nice for people to have a healthy body and with people appears to have a healthy body not fall among people and have seizures, and soon people will say, and if they see you anywhere they look at you differently because that’s how it is in our country.

Interviewer: How?

Participant: Well now it’s bad for my future, if you go and ask for someone’s hand (in marriage) or want to do something, it might be that because of this illness make others change their mind and say ‘don’t go, this boy has this illness and it might cause a very bad life for the wife’, it might become a reason.

Interviewer: If you come to that you want to get married, do you feel you can tell the girl or her family that you have epilepsy before you get married?

Participant: It seems very unlikely that the man is ill and the girl to accept him.

Interviewer: Why do you feel like that, for example, if your arm had something wrong with it, would it be ok?

Participant: It would be fine, yes.

Interviewer: Why do you feel this is affecting things more?

Participant: Because the girl is scared because she's thinking 'if we go shopping and walk around and if we go somewhere and he falls, I'm a vulnerable woman how can I overpower this man?'

Interviewer: How is epilepsy viewed in your culture?

Participant: Well what can I say?

Interviewer: For example if a few people talk about outside, how would they talk about it?

Participant: Well they would talk about it like something not nice. But the person who gets like that isn't in his control, those who talk about it know that the person who gets like that can't help it, it's an illness that's spread among people.

Interviewer: Is the illness looked at like a mental disability or physical?

Participant: Well so far it hasn't been made clear to me how it, it seems people might think 'what has happened to this person, maybe there's something wrong with them that's why they get like that' so it's looked at from the brain.

Interviewer: How has your life changed because you have epilepsy?

Participant: Well it's not nice, sometimes, I mean sometimes after I get like that anyone who talks to me I want to hurt them badly, but I am controlling myself.

Interviewer: In other ways how has it affected you, has it affected your friendship life, work, family?

Participant: Well, it hasn't affected me that much but once I was at school when I got like that in the classroom, I saw the pupils were crying and running away, because for pupils things like that is very hard, you are explaining things and then suddenly to fall, pupils get scared, they think you're dying there. They ran and said the teacher is dead go and save him, when they came they saw that I was on the floor, and since that day the teachers look me in a funny way.

Interviewer: How?

Participant: With fear.

Interviewer: Do you think they look at you as less since they saw that?

Participant: Well, what can I say but how do you say, I asked a girl (for her hand in marriage) and she told me straight away, she said 'I can't you have that illness'

Interviewer: You asked her for …

Participant: For marriage, yes, and she said ‘you have that illness I don’t think I can get on with you’

Interviewer: Was that her only reason?

Participant: That was her only reason.

Interviewer: The first time, although you were young when they first told you, but since you have come to realise what the condition is, how did you begin to accept it, how did you manage it?

Participant: Well this is one of the things, how do you say, it’s no choice, when it comes over you, you have to accept it, because if there’s a cure its best if you do it but if there’s no cure you have no choice but to accept it.

Interviewer: How did you accept it?

Participant: What can I say, I have to control myself more, those things in my head, or sometimes very angrily, afterwards when I get like that, I do my very best to calm myself down, I am in control a bit.

Interviewer: How do you calm yourself?

Participant: Whoever it is I say, I talk to myself in my head, I say so I did that, so I did that, I upset so and so, why did I hurt them, why should I hurt them, after 5 minutes I get better.

Interviewer: This is after your seizures, you feel more aggressive?

Participant: Yes, yes.

Interviewer: You control yourself at that time?

Participant: Yes, yes.

Interviewer: Do you feel that you view life differently because you have epilepsy?

Participant: Well I feel that I am different to other people.

Interviewer: How?

Participant: I say look if you see other people how nice their life is and they don’t have seizures, they’re not ill, they don’t have health problems, but when I see myself a fall on my face, I’m not aware of myself, I say even if I knew when it was it would be better but to be like that suddenly, whether you’re near fire, wherever you are you have fallen so by the time you get up your body is covered by bruises.

Interviewer: Do you think less of yourself because you have epilepsy?

Participant: Yes, yes I feel it, but sometimes I try and make myself feel better, I see someone disabled, blind or in a wheelchair, I make myself feel better, I talk to myself and say ‘look how he is, at least you walk with your own feet and your eyes are fine’ I make myself feel better with that.

Interviewer: How do you approach your life? How do you look at your life?

Participant: I like it, I like my life, I’m very comfortable.

Interviewer: Do you feel because you have epilepsy this has hindered you? In your progress in your life?

Participant: Well those things that hinder me, I have managed it myself not to hinder, I have to manage it myself.

Interviewer: Do you feel it has hindered you until now or have you progresses fine but the stress has been heavy?

Participant: Well that’s how it is, something’s come in your way that hinders you, like I say marriage and things like that, sometimes you go for marriage. A while ago I don’t know who it was they had said, my brother had got married, they had said that family, they had asked about the family, they had said well they have a son but he has regular seizures in the Mosque, and they thought it was me marrying the girl.

Interviewer: But it was your brother?

Participant: Yes, so it was my brother, that family whose daughter he was marrying had come to the neighbourhood to ask, you know when a girl and boy gets married they ask questions, they had asked how are the family, they had said they’re a very good family but if it’s that boy I’ve seen him have seizures a few times, they were a bit you know, and when they has asked more, they were told that it wasn’t me but another one that’s older.

Interviewer: So …

Participant: If it was me, it seems like it’s not very nice or not give him the girl.

Interviewer: Do you feel that you can tell people you have epilepsy?

Participant: Up until now I haven’t told anybody.

Interviewer: No one, friends, work colleagues?

Participant: I haven’t told anyone unless I have fallen in front of them.

Interviewer: Have you discussed it afterwards or talked about it or..?

Participant: And they say ‘‘what happened to you, we were shocked and scared, why did you fall suddenly’’ and then I tell them I’m ill and I’ve had it since childhood, then they say ‘‘why didn’t you say, why don’t you tell us, when you have something like that we should know,'' like the classroom, when I was laying there they thought I was dead, ''you should've told us sooner so we could look out for you.''

Interviewer: You don't even tell your friends?

Participant: I don't tell them until, how do you say, fall in front of them.

Interviewer: Do you feel they will look at you differently if they knew, if you tell them you had epilepsy?

Participant: Well, in this culture we have that, if they know you have epilepsy, or have a seizure in front of them, they look at you in a sensitive way.

Interviewer: How?

Participant: They look at you all the time, or look at you differently or make fun of you, sometimes if you do something even as a joke they say 'go, at least we don't have seizures and you do'.

Interviewer: You talked about that in your culture epilepsy is seen as something difficult

Participant: Yes

Interviewer: What else is there that affects whether you tell people you have epilepsy or not?

Participant: Well as I say I wouldn't be comfortable telling people, like I say, maybe its normal, other people have it worse than me, mine even if I fall my seizure is just that I fall and that's it, I don't foam at the mouth, I don't bite my tongue, I don't scream, but some people have that and its normal for them, for me, thank God I don't even have that but I still don't talk about it.

Interviewer: What's the most difficult aspect because you have epilepsy?

Participant: Well the most difficult thing is I don't know what to say, just for work and offices I don't like it, and marriage.

Interviewer: Today when you had a seizure, were you at work?

Participant: I was eating, the food was in my mouth and fell, when I woke up I had that much rice in my mouth, as I say I'm not aware, I had two spoonful in my mouth, as I say I'm not aware whatever happens to me, have rice in my mouth, stew in my mouth, near water, I'm not aware.

Interviewer: For someone who's just been told has epilepsy, how would you advise them?

Participant: How would the advice be? Manage themselves, in case they're like me don't get angry, don't get upset, don't hurt anyone, don't upset anyone, don't worry about life, pretend you don't even have this illness, empower yourself, make yourself strong, I would just say that to them, I tell myself that as well.

Interviewer: What would you tell them to make their life easier because they have epilepsy?

Participant: Don't stress too much, don't think about life too much, if they like something but can't get it don't worry about it too much. Our young people now they like cars and houses but if you can't do it don't worry too much and don't stress too much, that has a great effect on epilepsy.

Interviewer: Thank you. Do you have any other information that would help me or for this condition or for someone with the condition, or if you have something more to say?

Participant: Well for me now it's, I don't know what medication there is that is good for this illness, I have changed tablets and either have hit me really bad or medium or have no effects.

Interviewer: You want more information?

Participant: Yes, I want to know what tablet is good, what other ways, it doesn't have to be tablets, to know what I can do after the tablet so how you say, to forget this, because the doctor was saying I have to do something to forget this illness so that by the time you realise it has gone. In Sweden I was tested, I have it in an x-ray, the vein in my brain is bent in my head that was with a tunnel machine (MRI), they did all my body.

Interviewer: In Sweden?

Participant: Yes in Sweden, they did it for me. And they told me the same as here, I shouldn't stress, I can't think much, I can't have sour stuff, that's really bad for me, I can't sleep less I have to sleep more, food cannot be delayed, I have to eat on time, and not eat too much, they told me these things that is bad for the illness, oil is the first, sour I can't have.

Interviewer: This is the information from Europe?

Participant: Yes, although they told me the same thing here but in Europe I was reassured, in Europe it's the same as here.

Interviewer: Thank you very much.

Participant: You're welcome

Interviewer: For the information, I hope you're always well.

Participant: Thank you.

End of interview.

13.13. Kurdistan Participant 3

Kurdistan interview 3 M

Interviewer: How old are you?

Participant: I'm '76

Interviewer:'76, how many years is that?

Participant: 34 years.

Interviewer: 36, isn't it 36?

Participant: Yes

Interviewer: Are you married?

Participant: Yes

Interviewer: Do you have children?

Participant: Yes

Interviewer: Boys, girls?

Participant: Well 2 boys and 2 girls

Interviewer: How old are they?

Participant: One of them is 28th February 1999 my eldest daughter, one of them was born in 2000, the other one when Sadam was executed 2006 and the other 14th November 2006.

Interviewer: What is your occupation?

Participant: I'm a porter here.

Interviewer: How many years have you had epilepsy?

Participant: 2007, around 2006, my book finished, they renewed it.

Interviewer: Have you for about 9 years or did you have it before then?

Participant: No I didn't have it before

Interviewer: What do you think caused you this illness?

Participant: I don't know what caused it, sometimes I fall to the ground

Interviewer: In the day or night mostly?

Participant: In the day, but sometimes, err I haven't had it for 2 years.

Interviewer: You haven't had it for 2 years?

Participant: Yes

Interviewer: That's very good

Participant: Sometimes I get dizzy (points to his head), like that

Interviewer: How did you know that you had epilepsy? What happened?

Participant: I went to clinic, we were in Azadi (area) they took me to the hospital and did some tests.

Interviewer: What did they do?

Participant: Tests, then they said we'll give you a book, they gave me a book for these medications, I take one a day.

Interviewer: You take one a day?

Participant: Yes, this book had finished, I buy it in the market for 3000, this book finished a long time ago, I have been using this one, in the markets its 3000, these ones.

Interviewer: Is there any effect?

Participant: No, no I'm better, there's another one it's got 3 pieces, not like this one, this is the genuine one is for 3000, the other one is 2250, its 750 each.

Interviewer: How did you feel when they first told you you had epilepsy?

Participant: I had no feelings, I said you know, its god given, sometimes god gives us illnesses.

Interviewer: You weren't upset?

Participant: No. no, I wasn't upset. At the time we had two children, I had it a long time, until they took me to hospital they made me a book, then went to the hospital with my uncle they made me a book, near the university, close to the children's hospital, then they gave me this. Some days they give me 3 pieces a month, sometimes I go every 3 months then I used to go, it was in Kareza Wishk (area) we lived in Zargata (area) now we live in Kaniba (area), my book finished I buy this daily. Every 10 days for 3000, like that.

Interviewer: Before did you have any knowledge about epilepsy?

Participant: No I didn't know

Interviewer: Do you think you have accepted the condition and it was ok for you, what was the reason?

Participant: Nothing

Interviewer: How? Because you're very religious or you have heard of it before in your family?

Participant: No up until now I haven't heard it, no, it's God given, some people get diabetes, heart attack, thank God I haven't had it for 2 years.

Interviewer: Your good health

Participant: Thank god

Interviewer: What is your knowledge now on epilepsy?

Participant: Nothing

Interviewer: You have no knowledge?

Participant: I have no knowledge

Interviewer: How do your friends, your wife and family help you when you found out it was epilepsy?

Participant: Well, she came with me to clinics and stuff and she was good to me.

Interviewer: She helps you, how does she help you?

Participant: How do you mean?

Interviewer: Does she talk to you ….?

Participant: Yes, yes, yes

Interviewer: Does she remind you to take your medication….?

Participant: Yes, no when I wake up in the morning I eat breakfast I then take the tablet

Interviewer: Before, as you say you haven't had it for 2 years…?

Participant: Yes I'm fine, thank God.

Interviewer: How often did you have seizures?

Participant: Every 2 months, like that, sometimes once a week, like that, but thank God I'm better, I take this too (shows me another tablet pack), I'm better. Before it was two tablets, now I take one, and thank God, sometimes in the 3 months I get 90 tablets, that's means once a day, I would go every 3 months, now I take one a day, and it's better for me, thank God.

Interviewer: Do you have any feelings before you have a seizure?

Participant: Yes my head gets dizzy.

Interviewer: You get dizzy?

Participant: Yes

Interviewer: And then you lose consciousness?

Participant: Yes, I'm not aware, sometimes I go somewhere, I fall and they put me somewhere else, I'm not aware.

Interviewer: How long is it before you wake up?

Participant: 10 minutes, just that.

Interviewer: Yes. Do you think there is anything to cause you to have a seizure?

Participant: No

Interviewer: Stress or …?

Participant: No, I have no stress.

Interviewer: There's nothing and it just comes itself?

Participant: Yes just like that.

Interviewer: What about afterwards, how are you?

Participant: Nothing, it's normal, I can walk

Interviewer: What happens to you, do you get a headache…?

Participant: Yes, I get a headache.

Interviewer: Do you fall asleep or sleepy?

Participant: Yes, I get like that.

Interviewer: What do those around you do when you have a seizure?

Participant: Sometimes I don't get like that at home, you know when I'm walking, I fall to the ground

Interviewer: What do they do, do they help you …?

Participant: Yes, those people, the ones that are walking pick me up.

Interviewer: What do they think when they see you like that?

Participant: Sometimes, me I don't care sometimes, but I'm better, I get up, I sit up, I don't lie down, I sit up 10 minutes 15 minutes I get better.

Interviewer: And then you can walk normally?

Participant: Yes

Interviewer: Very good. Do you think you had any control over your seizures?

Participant: No, I have no feelings

Interviewer: Do you tell people you have epilepsy when you see them?

Participant: No, no, no, no one

Interviewer: You don't talk about it?

Participant: No, sometimes I work, I go home around 8 or 10, no one notices.

Interviewer: You don't tell anyone?

Participant: No, no

Interviewer: Is there a reason you don't talk about it?

Participant: No, well I don't tell anyone.

Interviewer: Why?

Participant: I don't want people to know, sometimes

Interviewer: What happens if they know?

Participant: Nothing

Interviewer: Do you think this has affected your life?

Participant: Effect? Little

Interviewer: Do you think people look at you differently if they know you have epilepsy?

Participant: Sometimes when I walk on the way, they say 'why did that happen to you' sometimes people say its epilepsy and stuff, and I say 'I felt dizzy', sometimes in the market, sometimes I walk I fall, when I get to the place they say 'why did that happen to you?' I say 'I fell and my head hurts'.

Interviewer: But you won't say?

Participant: I won't say, I won't talk about that

Interviewer: Are you shy or do you think people look at you differently…?

Participant: I'm not shy maybe other people

Interviewer: Misunderstand you?

Participant: Yes, yes

Interviewer: Is there anything you can't do because you have epilepsy?

Participant: I can, you know for work and stuff I can do it

Interviewer: Has it hindered you for anything?

Participant: No, no, no sometimes I get one (seizure), and sometimes we get delivery at night and normally I get the delivery and its fine, nothing happens to me. When I finish I go home normally

Interviewer: In your culture, in the Kurdish culture, how is epilepsy viewed?

Participant: Nothing

Interviewer: If they know someone has epilepsy, how would they view them?

Participant: Nothing

Interviewer: Just normally

Participant: Yes, just normally

Interviewer: What's the most difficult aspect of having epilepsy?

Participant: Nothing, that I don't know

Interviewer: For example, sometimes some days your head may hurt more … or have a seizure in front of people?

Participant: I sit down until my head gets better, I sit down and rest.

Interviewer: What about when people see you, is that difficult for you, is that more difficult for you or the headaches and the dizziness?

Participant: My headache is a bit better, if I rest now, if I get a headache I sit down so I don't fall sideway on the ground.

Interviewer: How would you advice those who are newly finding out that they have epilepsy? What would you tell them?

Participant: Nothing

Interviewer: You tell them anything?

Participant: No

Interviewer: Why? Not for you, for them, how to look after themselves, what to know and what not to?

Participant: Now we don't have anyone who has epilepsy and things like that.

Interviewer: Do you have anything else to tell me?

Participant: No.

Interviewer: Or to help me?

Participant: Just that, I'm renting, I pay 25000 in rent, here I get 500000, 25000 go in rent and 3 of my children are in school. It's like that, finished.

Interviewer: Thank you very much

Participant: It's no problem

End of interview

13.14. Kurdistan Participant 4

Kurdistan interview 4

Interviewer: How old are you?

Participant: 43 years

Interviewer: Are you married?

Participant: Yes

Interviewer: Do you have children?

Participant: 3 children

Interviewer: How old are they?

Participant: My eldest daughter was born 2002, after her my son was born in September 2003, I have another daughter born in February 2008.

Interviewer: What is your occupation?

Participant: I work for as a civil servant.

Interviewer: What do you do in your job?

Participant: When moving cars, I make cards for the drivers so they have permission to work in the vicinity, Chwarta to Sulaimania.

Interviewer: So you work in an office?

Participant: Yes

Interviewer: How many years have you been getting seizures?

Participant: Approximately from 2000, it's been 12 years

Interviewer: 12 years, do you know anyone else who has epilepsy?

Participant: From my relatives?

Interviewer: Friends, family, neighbours?

Participant: From my friends, there's another lady who's like that.

Interviewer: The same as you?

Participant: No, she has it much more difficult, she vomits, she has an aura, I'm not comfortable seeing it.

Interviewer: How is yours when you have a seizure?

Participant: No, I just shout and scream because of my head, you know I notice my body is stiff; my body is uncomfortable, like that

Interviewer: How did you know you had epilepsy, when the first time you had a seizure, what happened?

Participant: The first time was when I had just got married, about a year or so I had been married, because I got married end of 1998. It was the beginning of 2000 we were in a crowded place, one of my husband's relatives had got married, we were in their crowd and I felt my head felt very heavy, I had never been like that, my head heading that much, I went to my husband and told him my head feels really tight, he said 'maybe outside weddings, like in a village, is more difficult than Sulaymany wedding, they use drums and it might be the sounds that you're annoyed.' He took me away from the crowd and on the way going to the place I had fallen, if was from then when I came to in the hospital I felt that I had epilepsy.

Interviewer: How did you feel when you found out you had epilepsy?

Participant: I was very uncomfortable; I was very, very stressed about it.

Interviewer: What was the stress about mostly?

Participant: Because I feel when I'm sitting with other people, you know I don't trust myself to sit in that place completely, you know like a wake and you feel that they're close to you but you can't stay at the wake as you need to like everyone else to sit and know how you're doing things.

Interviewer: Do you feel that you're constantly nervous about when you're going to have a seizure next?

Participant: I feel, you know, I say 'I'm going to Sulaymany, I'm going to visit my father's (parents home)' my husband won't stand in my way and says go but I feel that he's frightened, he says go but he's frightened he says 'on the way in case she has a seizure in the car or on the way, God forbid, what I can I do, I will be shamed and I will lose my wife'. And myself I really want to go out but I'm frightened.

Interviewer: The shame you feel that your husband feels, is it for you or for him?

Participant: For him, he says if I allow you to go on your own and something happens to you on the way, people will 'see, the reason he's allowing his wife to do that is so she gets run over somewhere and he's free' he says that's what he's worried about otherwise he says the seizures are a gift from God, it's not in anyone's control, it's not through being brave or exhaustion that someone gets this.

Interviewer: What was your knowledge of epilepsy before you were diagnosed?

Participant: I didn't have any knowledge.

Interviewer: What about now, what your knowledge?

Participant: Now I feel those people (who have epilepsy) need to be taken care of, understand their difficulties, so what if that person is a man or woman, clearly, see where they are comfortable, create that environment for them, see what medication, see as much as you can use the medication, why is it so difficult? For me now, the medication the doctor has prescribed me, the doctor says you have to take this medication until you die. It would make me happy to know everybody looks for a treatment for their illness, whether the illness is physical or mental, I don't know, whatever they want, I want everyone, not just me 'just so let me live among my children' no, on the contrary I don't even want my children to see me when I get like that, so they don't stress about it because my daughter is a very intuitive person, and when she knows things she really stresses out, so…

Interviewer: When you first had a seizure and you found out you had epilepsy and had to take medication, how did your husband and you family looked out for you, how did they help you?

Participant: They helped me a lot, they took me a lot, even to Baghdad, to Mosul, to Kirkuk, they would take me.

Interviewer: To see doctors?

Participant: To see the doctors, I've seen many doctors in those areas, in Erbil, just to get some treatment, thank God these past years I've been very good, this year I've been a bit uncomfortable, and this year, believe me, there isn't a week that goes by that he doesn't take me to two doctors. And now for Saturday I have another doctor's appointment so he can see me to see what my treatment is.

Interviewer: Do you now have lots of seizures?

Participant: Now it's very frequent, sometimes I have 4 seizures, 5 seizures.

Interviewer: In a week?

Participant: In a week.

Interviewer: Is there any particular times?

Participant: No given time

Interviewer: Do you think there's anything that affects you that you have seizures?

Participant: Mostly when there's a worry in my head. When I stress about something I feel it straight away, I get upset.

Interviewer: Is there anything else that affects it, that you know of?

Participant: Crowding places. I can't go to crowded places, believe me, there are four of us in a room if they make it five I can't bear it, it shows on me, I get pale.

Interviewer: After seizures, when you wake up, how do you feel?

Participant: If I am at home, my husband or my children or my mum or dad, sisters or my own relatives and my husband is there, I accept it very casually, it's very, very normal, when I wake up I have an upset head, I tell them 'let me lie down for a bit, I get comfortable, I get better myself' then they feel its fine but if I'm in the office, no. I start crying, believe me, sometimes, I don't stop crying for two days.

Interviewer: Why, why does it bother you?

Participant: I stress about it, I say those friends, there may be people that don't like it that I get like that, or there might be those that make fun of me when I get like that, and maybe, how you say, feel sorry for me, or maybe my body has been exposed and the men see it, otherwise with the women even if my body shows it's no problem but as far as the men, no.

Interviewer: It makes you uncomfortable?

Participant: I get very uncomfortable.

Interviewer: What do those around you do, for example if you're at work if you get like that what do they do, if you're home what do they do?

Participant: Well they put me on a place where I'm comfortable, of course for me sometimes I'm sitting and fallen or standing and joking with them and fall and in those circumstances they put me on a place, and sometime they do that to me or they move my hand, they say to exercise my arms so it doesn't seize up in those times, often they tell me my hands get stiff, they open it for me, I pull at my hair, they take my hand off my hair and its fine.

Interviewer: Those around you, how do you think they feel when you having a seizure?

Participant: I think they feel sorry for me.

Interviewer: At home and at work?

Participant: Often I think that, and I also think there are one or two people at work, I feel when I have a seizure they talk about me, you know how they say, make fun of me.

Interviewer: Do you think you have any control over your seizures?

Participant: I feel I've been very successful over myself, in charge, like the doctor said 'in your circumstance, had you and those around didn't affect you that much you may not have been able to live like that', but I feel I find the strength inside myself, I say 'I'm like a human being like them, there may come a day when I won't need anyone, I might get better'. I like a lot of hand craft, knitting, making things, I really like it, like this (shows me the shawl on her shoulder), like in winter I make shawls for ladies, it's my dream, I'm very comfortable, very comfortable, because I feel like it makes me forget things, if I have a problem, straight away I pick up the knitting needles and I start knitting.

Interviewer: How did you accept that you had epilepsy, how did you begin to accept this condition?

Participant: One of my brothers had returned from Britain at that time and he talked to me a lot, it was about 2004 he came back, he talked to me a lot, he said 'this is an illness there's no need, first it's a gift from God, it's not to do with being brave or lazy, second every person who in life is open to illness, for funeral, these things that come your way daily, you have to accept these things'. When he told me these things I thought 'he's right, what is a person? You are born, slowly you grow up, then either with illness or health you live your life and then suddenly something comes and you die, what is the point of me stressing about it so much? That's life, it's how it's made'.

Interviewer: Do you think you can tell people you have epilepsy?

Participant: It's very normal.

Interviewer: To friends, family?

Participant: A lot of people, if I have met anyone, you know, to see someone and bump into them randomly, I have said 'if something happens to me don't worry as I have this'.

Interviewer: Do you think your life has changed because of your epilepsy?

Participant: Well what sort of changes? When you go anywhere they put you somewhere cautiously, you know they're cautious with you, one of my cousins passed away in December just past, because they knew things affect me quickly, 'you come and sit here, you go and do that, it's ok go and get comfortable upstairs, it's ok go to your aunts house to sit' they were using these things.

Interviewer: You think you were given special treatment, and you don't like that?

Participant: I don't like it when they put me over someone else, or in a crowding place, for example you wash the dishes 'you come sit down so you don't get tired let them do it'' and

I say ‘‘it hasn’t come to me from Shah to sit down, I have to move as well, I prefer to move around’ I don’t like discrimination, it’s not comfortable, I’m a bit uncomfortable.

Interviewer: So whether it’s in your favour or not you don’t want to be treated differently?

Participant: For the favour I like it, if it’s to cure me it’s another thing, but to separate you everywhere, you know, at my in-laws for example, there are 5 daughter in-laws together including me, I get up to work and my mother in-law says ‘you just come sit next to me and talk to me’ and I know why she’s discriminating against me but she won’t tell me to my face, you know, and it’s nice for me to converse with them as well, I might be more comfortable, I prefer to do the work, very, very, it’s my hobby, as soon as I wake up to clean my home until the evening, I’m comfortable.

Interviewer: Do you think epilepsy has affected how you view life?

Participant: Yes, when I didn’t have epilepsy before, I really liked visiting with relatives, you know friends, my husband’s relatives, I really liked it, you know if someone’s ill to go visit them quickly, if someone has a funeral to go visit them very soon, if someone has a daughter who marries go see them, if their son gets married go see them, but now it’s made like ‘let me not visit too much, let me delay things so my husband can be there with me in case something happens to me’ that has affected me otherwise with other things, no.

Interviewer: How do you feel about your life now?

Participant: I feel until I die I’m not going to stop trying, at work, in housework, with my children, with relatives, especially my husband, because he’s very exhausted with me, he’s very exhausted with me.

Interviewer: Do you think people see you differently, although you mentioned that some people treat you differently, do people, those that you don’t work with or are family, treat you differently because you have epilepsy or that you have seizures?

Participant: Well the difference is what, you know what I said about work, ‘give her time off because she’s not well, let them do this for her because she’s not like this’ or in the neighbourhood, ‘let her do this because she’s not well’ that discrimination is not nice.

Interviewer: So you feel it in most places?

Participant: Believe me, I tell the neighbours, ‘there’s a wake in so and so’s place let’s go’ I see them give four prayers and on the fifth they say ‘let’s go’ and the other one says ‘why should we go, we just got here? Let’s sit a bit longer because of the family’, ‘she’s not well, let’s go because of her’, it’s not nice for me.

Interviewer: Is there anything else you can’t do because of your epilepsy? Apart from those that you talked about

Participant: Well, what are the things? Just that I may not be able to be there for husband as needed, often he's not home until Thursday and by Thursday I may not be able to, to care for him as needed, my headache may start on Thursday, it might start on Monday or Tuesday and when it starts I won't get better that soon.

Interviewer: How many days do you need to get back to normal after a seizure?

Participant: After a seizure I'm fine, after an hour I get back to normal, I get up and do my work but the really bad headache makes me very uncomfortable, thank God… this shoulder hurts with it (with seizures) but thank God since I've been taking my medication I don't get that strong headache.

Interviewer: Even after a seizure you don't get that strong headache?

Participant: A little before a seizure, after a seizure no its fine.

Interviewer: In the Kurdish culture, how is epilepsy viewed?

Participant: As a disability, they think that person has a disability.

Interviewer: What sort of disability, mentally or another way?

Participant: They might view it differently, I don't know I've heard from a lot of people, no one has told me face to face, but that lady who had epilepsy she wasn't at work, I knew her, she used to be an old neighbour, when she used to have seizures 'oh leave her, she's fitting 12 months in the year', her husband wanted to remarry, not because that woman is bad, he just said he liked to have two wives, they would all say 'why shouldn't he remarry, 12 months in a year he has to take care of this woman until she comes to', seriously those talks are very hurtful. It's true she wasn't there but I have feeling, it's hurtful. It's very difficult.

Interviewer: What's the most difficult aspect for you that you have epilepsy that may have affected you?

Participant: Well the difficult thing is just that not to get like that at work, because usually at work there are men and women, and women, you can't constantly wear big pyjamas underneath, I'm human I want to dress nicely, I can't use all these things, I don't want them to see me otherwise I have no problem with it.

Interviewer: If it's that difficult, have you thought about leaving work and staying at home because you have epilepsy?

Participant: Yes and this leave is because of that.

Interviewer: How long is your leave for?

Participant: A year.

Interviewer: And is it ok for you?

Participant: Its fine for me because at home I’m sure I can get used to the things, and in that year, I will do something, if I don’t die, I will do something that I will either get cured or I have 18 years service I will retire myself, if I feel that I can’t accept it, and if a can accept it I will go back to work.

Interviewer: What is your advice for those who are finding out that they have epilepsy? How would you advice them

Participant: To visit their doctor as much as they can, take the medication and precautions set by the doctor, thank God since the doctor has told me I feel I’m a lot better than before, in the last weeks five times, as I told you, up to four times I would have a seizure, thank God this week, it’s now Monday I haven’t had an episode yet, because the things the doctors telling I’m doing as he’s telling me, where to go, what to do, what to eat, I do it, I listen to the precautions, I will accept the doctors diagnosis, and I ask of those who are newly diagnosed not to take life too seriously, because life is just that, you’re born, you live, maybe while you’re young or maybe get to an age, maybe healthy or have ill health and die, so life isn’t that to stress about it too much, because those who want you while you’re healthy, I’m sure they will still want you when you’re ill, and those who hate you, if they hate you when you’re ill they’ll still hate you if you’re not, so why bother myself with them too much? And those who are newly diagnosed should view it the same way. Just like how people get a cold, get a headache, have a stomach ache, should accept epilepsy normally, epilepsy is an illness, it’s a brain illness.

Interviewer: Do you have anything more to add to help me, my research or those who have this condition or for the condition in general?

Participant: Well, for the families who have a patient at home, to help them a lot, understand them, understand what upsets that person, what really makes them happy, they should understand them, after they understand them, when you understand them, if she’s uncomfortable at her sister in-laws its ok don’t take them, it’s very simple, ‘sister the reason I’m not bringing my wife is because she’s not well’ and you should understand them, so what for a while let her not to visit, and take it normally, secondly take them to the doctors a lot, find out what the doctor is giving them. First they, find out what makes them happy and unhappy, and then take them for a diagnosis, the doctor can do that, and don’t look at those with epilepsy as less, they’re the same as those who are living, this one is suffering from back pain, this one has headaches, and they have head pain, its normal. Thank you, I put you out.

Interviewer: Thank you.

End of interview.

13.15. Kurdistan Participant 5

Kurdistan Interview 5 M

Interviewer: How old are you?

Participant: I'm 21 years old

Interviewer: Are you married?

Participant: No

Interviewer: And you don't have children?

Participant: No

Interviewer: What is your occupation?

Participant: I'm a student

Interviewer: How many years have you had epilepsy?

Participant: Since I was a child but it was cured until I was, until I was …

Interviewer: What age was it diagnosed?

Participant: What age? At an early age, I was young I didn't know but then I had a seizure in primary, year 1 (6 years old) they treated me in the paediatric hospital then after that in year 6 (12 years old) in primary again I got like that again.

Interviewer: You were about 6 or 7 years old the first time?

Participant: The first time yes I was 6 years old then after at the age of 12 it started again

Interviewer: It started again? How long were they able to control it before it returned?

Participant: For how many years? For about 6 years, they took water from the back of my neck and they cured it.

Interviewer: How was it when you got it the first time? What was the reason?

Participant: What was the reason? The reason was that when I first got like that, I noticed, my teacher was a bit mean with me, and that …

Interviewer: Mean how?

Participant: Like something, I don't know if he slapped me or what it was, then when I came home, I don't know if I stressed about it or what happened and then at home around the evening I got like that around the toilet.

Interviewer: You were young then but the second time you were again told how did you feel?

Participant: The second time it was when I was in primary year 6, I was working at the bakers in the summer, in the morning I was trying to go to work, before I went to work at home I got like that, at the time, when I realised I fell to the ground, then I was unconscious.

Interviewer: How did you feel when you got like that again?

Participant: How did I feel? I would be like that about 15-20 minutes then I would come around, my chest was hurting a lot.

Interviewer: Did you feel anything before you got like that?

Participant: No

Interviewer: There wasn't anything, any symptoms for you?

Participant: No

Interviewer: Did you have any knowledge about epilepsy, not the first time as you were young but the second time when it returned?

Participant: No I didn't have much knowledge

Interviewer: What about now?

Participant: Even now, I don't have that sort of knowledge

Interviewer: How are you now, do you have regular seizures?

Participant: Since March I got like that, when I got like that, that was at home too, when I got like that, but this time it took about 10 minutes because of the tablets that I take, after when I came round my chest didn't hurt.

Interviewer: It didn't?

Participant: This time it was different to all the other times?

Interviewer: How?

Participant: The other times when I came round my chest was very tight, I had a really annoying pain but this is when I got like that and came round I didn't have the chest pain.

Interviewer: Did you have any other pain?

Participant: No

Interviewer: Any other feeling for your body or head?

Participant: My head was slightly heavy but just that, the other times my head felt heavy and my chest would hurt.

Interviewer: How did your family, friends and relatives help you?

Participant: My family are really good, especially my mum, my dad, my sisters and brothers are very good

Interviewer: How do they help you, what do they do for you?

Participant: What do they do for me?

Interviewer: To make things easier for you

Participant: They always remind me to take my tablets, my mum puts my tablets down with every meal, even if I go out to a relative's house she says 'don't forget your tablets' sometimes they call me and say 'take your tablet so you don't get like that'.

Interviewer: Do you think there's anything that affects you to have a seizure? Daily stuff that happens?

Participant: Bad stuff?

Interviewer: Bad stuff, news

Participant: No

Interviewer: There's nothing?

Participant: There's nothing

Interviewer: What do those around you do when you have a seizure?

Participant: Those around me, there was once I was in primary, no in secondary I think, when I got like that, I was going towards school, I got like that close to our home, the neighbours around our home picked me up and they took me home, they were very good.

Interviewer: How are you when these people come to your aid, how do you feel?

Participant: I'm very happy that someone helps me when I have this illness.

Interviewer: How do you think they feel when they see you like that?

Participant: Of course it's not a nice feeling towards me

Interviewer: How?

Participant: It's not nice, that someone with a healthy body falls suddenly and get like that with books it's not nice.

Interviewer: Do you feel you have any control over your seizures?

Participant: No

Interviewer: That you can control so you don't get like that?

Participant: No, no feelings

Interviewer: How did you accept that you have this illness?

Participant: How could I accept it? This is something that God has given me, each person has a different illness, and is in agony with a different pain, but my pain is different to all the others pains.

Interviewer: How? Do you feel different to other people?

Participant: Like I look at myself less?

Interviewer: Just to feel different, or feel less?

Participant: No, I can do whatever people can do, whatever people can do I can do it too.

Interviewer: Has it hindered you, this illness that you can't do, if it wasn't for this you could've done?

Participant: For work?

Interviewer: For work …?

Participant: For work, at the moment I work in the summer season, I work as a ceiling decorator.

Interviewer: So it hasn't hindered you?

Participant: No, in the work place, thank God it hasn't hindered me

Interviewer: Can you tell people that you have epilepsy? To friends

Participant: In my friends, up to now only one of my friends know, and he only found out this year.

Interviewer: How did you tell him, what happened?

Participant: I had one friend and we came to the hospital at lunch time, we finished school and I said 'come on let's go' he said 'what is it?' I said 'come on let's go and pick these medications' he said 'why?' I said 'it's for this sort of illness' I told him 'I haven't spoken about it to anyone and you don't talk about it to anyone'.

Interviewer: And what did he think?

Participant: He was, of course it's not nice for him, it's not nice for him and it's not for me.

Interviewer: Do you think he's changed with you since he's found out?

Participant: No, he's better but not worse

Interviewer: Do you think your life has changed because you have epilepsy? For example since you got it again in year 6 your life has changed that it has affected you?

Participant: No

Interviewer: How do you feel about your life now? How do you approach life?

Participant: My approach is I would like a cure for this illness, a lasting cure that even those who get like that to be cured.

Interviewer: Do you think that if people know, as you said you've only told one of your friends, do you think other people will treat you differently of they know?

Participant: No, even with the relatives, the ones who may have found out is two of my uncles and one of my aunts, and my other uncles and other aunts don't know

Interviewer: Why is that?

Participant: Because I don't want them to know, I don't want them to

Interviewer: What's the reason?

Participant: The reason? I just don't want them to know.

Interviewer: Is there any reason that you don't want them to know?

Participant: Any reason? Well what can I say, I don't want them to know

Interviewer: Is it to do with people and your culture? Kurdish culture and how epilepsy is viewed?

Participant: Of course it's to do with it

Interviewer: Explain that to me, in the Kurdish culture if someone has epilepsy how are they looked at?

Participant: Well obviously if you come face to face with an unfortunate event, its, they might say something bad about that illness that you have

Interviewer: Like what?

Participant: Like 'go and may epilepsy get you again', it's not nice, it's not a nice word to use.

Interviewer: Is the word epilepsy not nice or the meaning of the seizures?

Participant: It has a bad meaning

Interviewer: Why?

Participant: Well what can I say? That I don’t know.

Interviewer: I would really like to understand because I don’t live here and I want to understand people’s views completely because I will compare to foreign views.

Participant: All I’m saying is it has a bad meaning

Interviewer: Just that?

Participant: Just that

Interviewer: Ok, what’s the most difficult aspect of having epilepsy?

Participant: You mean …?

Interviewer: What is the most difficult thing in your life because you have epilepsy? What has it made difficult?

Participant: What has made it difficult? Now what has made it difficult, at the time of studying I want to be in a place that is very, very quiet, where there’s no noise, and then if there is any noise I can’t study, and after that if there was no epilepsy people’s brains would be better.

Interviewer: How?

Participant: Peoples brain, in terms of thinking it would be better, in terms of understanding it would be better, in terms of these tablets that you take you need more sleep, if you don’t take the tablets you don’t sleep that much. I have friends who say they sleep 6 hours a night, or 7 hours, I have to sleep 8/9 hours, if I didn’t take those tablets of course I would sleep less.

Interviewer: You would have more time for studying and other things?

Participant: Yes

Interviewer: What advice would you have for someone who has just found out they have epilepsy?

Participant: I would advice that they get treated as soon as possible, until it hasn’t developed into the more difficult stages, the easy stages would be treated quicker. One of my cousins’ is about a year old, going on 3 years was given treatment and thank God is cured, he’s cured, but if that was not treated early, of course it’ll get worse, the illness will get worse.

Interviewer: What other advice would you have to be able to accept the illness and be able to carry on ok?

Participant: I would advise them that this illness is such that you have to accept it, accept it, and now that it’s being treated it’s very good.

Interviewer: Do you have anything to add or to help me or other people?

Participant: No I don’t have anything else, no.

Interviewer: Ok thank you very much

End of interview

13.16. Kurdistan Participant 6

Kurdistan interview 6

Interviewer: How old are you?

Participant: I'm '74

Interviewer: You were born in '74?

Participant: Yes

Interviewer: That's means you're 38 years old?

Participant: 38 years

Interviewer: You're married?

Participant: Yes

Interviewer: How many children do you have?

Participant: I have 6

Interviewer: What is your occupation?

Participant: I'm a housewife

Interviewer: How long have you had this illness?

Participant: A very, very long time, it's more than 10 years

Interviewer: More than 10 years?

Participant: Yes, I have been to many doctors and clinics, I went here and went there, there was no point

Interviewer: What do you think caused it?

Participant: I don't know, some say it's because of stress, some say, I don't know, I just got it, I don't know

Interviewer: Do you know anyone else who has this illness?

Participant: This illness? A lot of my husband's relatives are like that, but mine is a lot, my epilepsy is a lot.

Interviewer: How?

Participant: Sometimes, this Friday we went out I got it four times in the open.

Interviewer: Do you use medication?

Participant: Yes, it's been about a month the doctor has given me treatment, it's a small tablet, I have it now (takes out medication from her bag) when I was taking it it made me very dizzy, really down, and a heavy head, I stopped taking it for a while, I thought it was the medication, he gave me another one, this one (shows me her medication) I've run out, I've run out of this one but this one, my head is constantly down, it makes me sleepy, drowsy.

Interviewer: So you don't take it?

Participant: I took one today, the doctor said 'it's got nothing to do with that, take it', but I told him 'it is to do with that, when I take it it makes me drowsy, really down'. Sometimes we have guests and when I take this tablet I don't have the energy to socialise with the guests, to make food, it makes me down.

Interviewer: But it stops it?

Participant: Yes, it stops, I'm better, the seizures are better but I get drowsy, I get drowsy

Interviewer: When they first told you you have this illness, how was it, did anything happen around then, did anything happen regarding the family?

Participant: That day when I got like that, my husband's nephew was with me, my husband wasn't with me, he said 'how, why did this happen to you auntie? Do you not go to the hospital, clinics, why don't you take care of yourself?' I said 'dear, I go to the hospital a lot but the medication I take has no role'.

Interviewer: What about when you first found out?

Participant: The first time?

Interviewer: When you found out you had epilepsy, 10 years ago?

Participant: At the beginning it wasn't that much, it wasn't controlling me, it was better, but now it's been about 3 years, my seizures are a lot more and it's upsetting me. And I don't know, I went to the doctor the other day he was saying 'it seems that you are stressing' I said 'stress, it's only me and my children, myself, my children and my husband'.

Interviewer: How did you feel when they first told you you had epilepsy?

Participant: I told the doctor, there's an Arab doctor here, because he did the book for me, he said, he gave me the treatment, the treatment were different, I didn't get better so I brought them back with my sister and he changed it, he changed it to this one.

Interviewer: What about the first time, how did you feel when they said you have epilepsy you have to take medication for a long time?

Participant: He said you have to take medication but these medications we'll prescribe for you, you can't get pregnant, because it's bad for the pregnancy.

Interviewer: Did it upset you?

Participant: For that? Yes, when he said you can't get pregnant, I said 'can I not at all or would my uterus decompose?' he said 'nothing happens but you can't get pregnant' he said 'it's bad for the baby, otherwise the baby would be deformed'.

Interviewer: Was it because of this you were upset?

Participant: Yes, well I was upset about this and because of the illness I was very upset. Sometimes I get guests I pour the tea and then have seizure right there, it's really upsetting, I'm very down.

Interviewer: Before you found out you had epilepsy …?

Participant: Before I get it I have a slight headache, I get a headache any my eyes go black, it brings me down, I can't be bothered with anything, the children talk to me but I get so annoyed.

Interviewer: Did you have any knowledge before on epilepsy?

Participant: I had knowledge but not like that, sometimes I wouldn't get like that for a month. I don't want to get like that every day, especially with strangers, with relatives, it really upsets me, and that's what I'm stressing about, the other day, as I said, my husband wasn't with me, I had my husband's nephew and his wife with me, they were really upset, they said 'why don't you take care of yourself, how long have you been like that?' I said 'I'm like that but, I go to doctors, more or less.'

Interviewer: Why does it upset you for people to know?

Participant: I just don't like it when people are like that with me.

Interviewer: Why?

Participant: I just don't like it, they say 'what is it, what is that illness you have?'

Interviewer: Do you have knowledge on your illness?

Participant: Well I have the illness, as I said I got it four times the other day. My husband doesn't like it, he says you do it to yourself, he says you do it to yourself.

Interviewer: How do your family and friends help you?

Participant: My family and friends, at home I have no one with me, it's just me and my children, sometimes when I get like that it gets me for about 10 minutes, the children put my head on a pillow until I get better, they won't come near me, my eldest daughter tells them not to come near me until I get better.

Interviewer: How do they feel when you have a seizure?

Participant: It upsets them a lot, yes, my youngest daughter sometimes just sits around me and cries. We have a young daughter, she's 5 years old, sometimes she cries with me and comes under my cover, they cover me with something at home, it really upsets her.

Interviewer: Is there anything that affects you to have a seizure, bad news, tiredness?

Participant: That year my brother, my eldest brother got ill and he was very ill, he was at deaths door, he stayed in hospital for a long time, and I really love him. I got word, they said 'your brother's in hospital, he's so ill' and I used to walk a lot in the morning, and we live far, we live in Chwarbax and they live in Hajji Awa (areas), I used to go see him every morning, my vision became black and I hit the ground, and I got so troubled, my mum said 'what is it dear, why are you so off colour?' I said 'I hit the ground on the way and I've been sitting by the side of the road for 15 minutes', she said why are you coming on your own?' and I said 'I didn't have anyone with me, I couldn't wait' and I only got it that year.

Interviewer: Do you feel you have any control over your seizures? That you could stop it if you didn't want to get like that one day?

Participant: No, dear whenever it comes over me I get like that, it's not in my hand, if it was in my hand who would want to be defeated?

Interviewer: How did you begin to accept it? How did you begin to live with it?

Participant: Well with this epilepsy it really upsets me, I don't like it, it really upsets me.

Interviewer: Do you think you've accepted that you're ill and you have to take medication and have to look after yourself?

Participant: It's about 3 years since I've had that book, my medication has no purpose, the ones I take, no purpose. I have a medication, when I take it it makes me really drowsy, I don't want to lift my head off the pillow, and as you know those who have children and work you have to constantly do things for the children, but I take this medication, this tablet (shows me tables) it won't release me, it makes me drowsy, drowsy.

Interviewer: Do you tell people that you have epilepsy? Your relatives, neighbours?

Participant: All my relatives know

Interviewer: Have you told them or have they seen you?

Participant: Sometimes I go to my mums and I sit and by the evening I get like that, my vision gets black and I get like that. That day I went to a clinic, my sister lives in Sabun Karan (area) I got like that in their house, she supported me under my arms to put me in a taxi. Like that, whenever I get it I get, as I said that day we went out I got like that four times.

Interviewer: Has your life changed because you have epilepsy?

Participant: I don’t like my life at all, the epilepsy really upsets me.

Interviewer: How has it affected you, what has changed, or how has it hindered you?

Participant: I get headaches, I get upset, I don’t like to get like that, it really upsets me a lot, my husband really stresses about it too, he says the children are very upset.

Interviewer: Do you think people look at you differently because you have epilepsy?

Participant: No dear, I never talk about it with my neighbours, if I have guests and they see it otherwise I don’t talk about it, but my parents know.

Interviewer: Do you think they treat you differently, look out for you more or feel sorry for you?

Participant: I don’t know, I don’t know if they know or not but I don’t socialise with my neighbours too much but when I go to my parents, my mum always says ‘why don’t you think about yourself?’ I said I want to go to Hawler (Erbil), my brother said if you want to go he’ll come with me to take me to Hawler, let’s see what they tell me there.

Interviewer: Hopefully you’ll get better. Is there anything else that is difficult, apart from not being able to have children, is there anything else?

Participant: In the evening we had a guest at home, he was saying that ‘you’re probably upset because you’re scared your husband will say he wants to remarry?’ I said ‘I would like him to not only to marry one but two wives, why is that problem?’

Interviewer: Why should he get married?

Participant: We don’t have sons, and they say ‘Haji wants to get married’ I’ve been to Haj too, people crowd me like that and joke with me, they say ‘Haji wants to get married that’s why you’re stressing, you’re doing that to yourself’, it really bothers me when people tell me that.

Interviewer: Do you think it’s because of the illness that’s why they’re telling you this?

Participant: No

Interviewer: Or is it because you have daughters?

Participant: When they come to our house his sisters and relatives they tell me as a joke but I don’t like it, yes, I don’t like it.

Interviewer: In Kurdish culture how is epilepsy looked at?

Participant: In Kurdish community, no one has said anything to me about having epilepsy, no one says anything.

Interviewer: What do they think? Before you had epilepsy, what did you hear?

Participant: They don’t tell me anything, if I get like that at my mum’s or my sisters, they never talk about it, but my sister did say to me the other day to ‘think about myself and its unfair you get like that and your children are young’.

Interviewer: What’s your advice for those who have just got epilepsy and been told they have epilepsy?

Participant: What would my advice be, my advice is I say ‘God please take this illness away from me and I don’t want anything else from the great God’.

Interviewer: Is there anything that may benefit me or this illness or people with epilepsy?

Participant: What benefit, dear, he said ‘go and do a heart test and I will prescribe you medication but you can’t get pregnant’ and I said ‘pregnancy is not important God willing I’ll get better, I have 6 I don’t need any more’.

Interviewer: Thank you very much

Participant: It’s no trouble

Interviewer: I hope you get better.

End of interview

13.17. Kurdistan Participant 7

Kurdistan Interview 7

Interviewer: How old are you?

Participant: I’m ‘87

Interviewer: You’re ’87? That’s means you’re 25 years old?

Participant: About

Interviewer: Are you married?

Participant: Yes

Interviewer: Do you have children?

Participant: I have two children

Interviewer: What is your occupation?

Participant: I’m a housewife

Interviewer: How long have you had epilepsy?

Participant: Since after I got married

Interviewer: How many years is that?

Participant: I've been married for 4 years, after a week of being married I got it

Interviewer: What was the cause?

Participant: As for a cause I don't know but they tell me I've been frightened or stressed, the doctor says its stress, but I don't know, some people say you've been frightened, it was before my 40 days when I got it, they say its fear.

Interviewer: Do you know other people that have epilepsy?

Participant: Not many, I don't know, they talk about it but it's not like I've seen it myself, to be aware of it myself, but it's been discussed.

Interviewer: How did you feel when you first found out you had epilepsy?

Participant: I was really down about it, I really stressed about it but now I'm ok, I'm used to it.

Interviewer: Why were you so stressed about it?

Participant: It was really bad, I couldn't walk, or in hot weather, I'm still like that but at the beginning I wasn't used to it, I was really stressed about it, I couldn't take part in a party or picnic, when I'm tired I get like that, but now I'm a bit better, I'm used to it now.

Interviewer: Did you have any knowledge before on epilepsy?

Participant: No

Interviewer: What about now?

Participant: Well, now because I've got it, even if someone says I have a relative who's like that I say don't worry about it, because I've seen, I've been like that, so I don't know, bit by bit I've got used to it.

Interviewer: How did your family or you're your friends help you …?

Participant: They help me a lot, my dad, whatever he can do he will, my husband.

Interviewer: Like what?

Participant: So, if I've needed to see a doctor they've taken me, to see a mullah, if someone has said they're good, they've taken me, they've helped me, to a sacred grave, so I get better and it really stresses them out, more than me, so, however they could they've helped me. And they make me feel better.

Interviewer: Do you take medication?

Participant: No, I haven't used anything

Interviewer: How are you now, do you have regular seizures?

Participant: I've been ok for a while, it's been about a month I have less seizures

Interviewer: Do you have any feelings before you have a seizure?

Participant: My heart races, I have a headache, I get upset, I feel down

Interviewer: What do you thinks affects you to have a seizure? Is there anything …?

Participant: For me it's a lot … if I have a headache I will have a seizure, if I stress about the smallest things, if someone says the smallest thing to me I get like that, so if I am at a party and I get tired, or walking and I get tired, or when I do housework, just housework I get tired and I get like that.

Interviewer: How are you feeling after a seizure?

Participant: If I am not aware and I fall to the ground, when I come around I'm very tired and down, my whole body aches, but sometimes I sense it and I go to the bedroom and lie down, when I wake up I feel rested, I feel like I have rested.

Interviewer: What do those around you d when you have a seizure?

Participant: I'm not aware of them but it upsets them, when they talk about it.

Interviewer: How do they talk about it?

Participant: They look after me, they're over me until, but I don't know some of them put water over me, my uncle was abroad and he came back he said don't put water on her it's not good, but just to hold here (points to her forehead between her eyes).

Interviewer: Where?

Participant: Here (points to her forehead between her eyes).

Interviewer: Between your eyes, why?

Participant: He said hold it gently and she'll get better, so now they tell me they do that and I come around.

Interviewer: How do you feel about those around you when you're having a seizure?

Participant: How do they feel? They're very sentimental, Kurdish people are as you know, it upsets them, but I'm not aware, as I told you when I have a seizure I'm not aware, some people say they hear things, but now, one of our in-laws her mum is like that, she says her mum says she hears everything when she has a seizure, but I don't hear anything. Once I heard my daughter crying over me it really upset me, otherwise I'm not aware or feel anything

Interviewer: Do you feel you have any control over your seizures?

Participant: No, nothing

Interviewer: You have no control?

Participant: None, sometimes I sense it coming I want to sit in a conformable place, I fall straight away, it's really upsetting, I don't even feel it.

Interviewer: How did you start to accept this illness?

Participant: Bit by bit

Interviewer: What made you accept it?

Participant: My dad and them lot would talk to me a lot, they'd tell me not to stress about it, don't worry about it, you'll get better, we'll help you, so bit by bit until I got used to it.

Interviewer: Do you tell people you have epilepsy those you know?

Participant: Yes, I don't have a problem

Interviewer: It's ok for you?

Participant: Everyone knows I get like that

Interviewer: Do you think your life has changed because of your epilepsy?

Participant: Yes, very, there are a lot of things I can't do in case I have a seizure. Before I used to go on my own to Sulaymany, if I needed something for myself I used to go do it and come back, but now I can't, it has stopped me from doing a lot of things, I can't do it on my own, whatever I want to do, someone always has to be with me, it's not nice for these things

Interviewer: How do you feel about your life now, if you compare it to when you didn't have epilepsy?

Participant: It's not nice, but you have to be tolerant, I'm used to it otherwise its very upsetting, when I think about it because, to be honest I don't have the energy to do my own housework, today I washed two bed covers I got like that. I can't, if I get a bit tired I can't, I can't tolerate it, if someone says something to me I have a seizure straight away, if I have a headache I have a seizure, if my heart races I have a seizure straight away, I don't know, or if I see something, something frightening I get like that straight away.

Interviewer: Do you not think medication will have an effect?

Participant: I went to see a few doctors they said just stress, there's no cure, they haven't prescribed me any medication and I haven't used any, but my grandmother was saying, my uncle, the uncle who came back from abroad tell me a lot 'let me take you to Tehran they have medication' I said ' I can't leave my daughter' I didn't go, he said 'you'll get better with one pill, if you take one pill', but up to now I haven't used anything.

Interviewer: Is it your decision that you're not using anything?

Participant: Well, myself

Interviewer: Do you not believe it or …?

Participant: If there is I believe it, if there is something and I know it's a 100% good and I'll get better, but up to now a few doctors have said just don't stress, I haven't been given any medication, that's how it is

Interviewer: Do you feel that people look at you differently if they know you have epilepsy?

Participant: What I don't like is when they feel sorry for you, I don't like that, a lot of people when they see me, they said 'oh poor you' I'm used to it but when they tell me that it really upsets me, it's not nice for me, or in front of my mum when I get like that, once when I came round my mum and dad were crying over me, it really upset me.

Interviewer: In Kurdish culture how is epilepsy looked at?

Participant: How do they say, you have fits, it's not a nice thing because I don't know, how to say they look at it but if you say 'I have epilepsy' they say they have fits, or something like that. Mine it's not even that, they say you don't strike with your hands, some people when they have a seizure they strike their hand, they tell me I'm quiet, I have a quiet seizure and wake up quietly, but lately when I have a seizure and I come round I cry, for a while I cry, I don't know.

Interviewer: You get upset?

Participant: Or I'll be quiet, even if they talk to me I can't answer, I hear them talking to me but it's not in my hand I can't say anything.

Interviewer: What's the most difficult aspect of having epilepsy?

Participant: How do you mean?

Interviewer: Like, what's the most difficult part, what's changed, for example, something that is important for you to do, or held you back?

Participant: It holds you back, in a lot of things, like I say, if I like something I'm telling you I can't do it, something like before I get like that I used to do things but now I can't because I don't think I can do it, I'm telling you the smallest things at home I can't, when I get tired that's it, if I want something, it takes time and energy, if I want to do something, even work, if I like to do a job, for people, I can't, because I get tired, they say because of my epilepsy, my dad and them, I've worked for people, but they say 'leave it, you can't handle it' and that's not nice for me, I can't…

Interviewer: Is it the discrimination you don't like?

Participant: Yes, I can't do anything to even try for my own life, thank god I'm not saying I'm poor but it's nice for everyone to be able to do their work, I was a student I left it

Interviewer: Because of your epilepsy?

Participant: I had my daughter and I was having a seizure every day, my seizures, they would bring me home from school, then I thought it can't be done, with my children and seizures its best to leave it. It's held me back from a lot of things.

Interviewer: What is your advice for those who are finding out they have epilepsy?

Participant: What would my advice be? I hope no one gets this illness, it's a bad illness, every illness is bad but this is different to other illnesses because you might get like that in a busy place, not know anyone, be on your own, it's not a nice thing but I hope no one gets it but those who have got it may God help them, I hope the ones who are like that get better, tolerate the circumstances and get used to it and not stress about it. It's a simple thing, God has given to us, not to have any problems

Interviewer: Is there anything else to add that may be important about this condition?

Participant: I don't have anything, I just hope those who are like that to get better, because it really holds you back, it's very upsetting, I feel I'm like a prisoner when I'm on my own, because I can't if I don't have someone with me, if I want to go to Sulaymany, for a holiday a visit I have to call someone if my husband is not home, to say 'will you come with me?', because tonight my husband is at work I've had to come here so I'm not on my own, I'm always on my way, even at home I'm not rested, in case I have a seizure and not be aware of my children.

Interviewer: Is this your parents?

Participant: No my in-laws, so the travelling is very frustrating for me, I hope no one gets it and those who have may God help us.

Interviewer: Thank you and I wish you good health.

Participant: Thank you

End of interview

13.18. Kurdistan Participant 8

Kurdistan Interview 8

Interviewer: How old are you?

Participant: I was born in ‘67

Interviewer: So that’s about …

Participant: 44 years

Interviewer: 44 years, you’re married?

Participant: Yes

Interviewer: How many children do you have?

Participant: I have 3

Interviewer: What is your occupation?

Participant: I’m a housewife

Interviewer: How many years have you had epilepsy?

Participant: What can I say, 25 to 30 years

Interviewer: Do you know anyone else who has epilepsy?

Participant: You mean in my family?

Interviewer: In your family, friends, neighbours?

Participant: No, just my husband and my son has had it in the last couple of years

Interviewer: What happened around that time that you got epilepsy?

Participant: I had an accident, I mean my brother got run over by a car, he was 12 years old, I got it from that, when I got it I went to the doctors a lot, they kept telling me you’ll get better, they kept telling me, I used a lot of medication, they kept telling me I’d get better and I still didn’t get better, year by year and day by day I got worse. I mean sometimes in the month I’d have it 2 times 3 times, sometimes 5-6 times, it was dependant on the month, I went to the doctors a lot, I took a lot of medication, even until now I’m still taking it.

Interviewer: When you first knew you had epilepsy, how did you feel? How did you take the condition?

Participant: How did I take it? It was very upsetting because that illness, whether you say it or not it’s a bad illness, I mean you get it suddenly, you could fall in fire, a lot of times, sometimes I’ve even burnt, I would be standing up unaware then suddenly fall on stone or fire I’ve fallen on it. I mean those instances have been very upsetting.

Interviewer: Did you have any knowledge on epilepsy before you were diagnosed?

Participant: You mean before I was diagnosed?

Interviewer: Before you got it

Participant: Before I got it, I would get upset, I would get distressed, I would suddenly get bad, I mean like you would be sitting there and I would trying to call you and I would be voiceless, suddenly, I would be aware for the length, I would raise my head and call you, I would lose my speech, when I lost my speech I would fall to the ground.

Interviewer: How is your knowledge now on epilepsy in general?

Participant: Well my knowledge, what can I say?

Interviewer: Do you know from being explained to by doctors of what it is and how it is?

Participant: They say it's an illness that's temporary, they say its temporary and you'll get better but some people get better and some people don't get better, yes, some people when they take the medication it stops it or it lessens month after month, or it gets less its better, and some people will have it permanently.

Interviewer: When you were first diagnosed what help did you get from you family and friends?

Participant: They all helped me a lot, especially my husband, if I say he was better than all of my relatives it's not a lie because he was very good with me, even now he's really good with me, yes, he's really helped me, the more I compliment him it's not enough because he's gone beyond necessary, he's helped me.

Interviewer: May you always be together.

Participant: Thank you

Interviewer: How are you now, do you still have seizures?

Participant: Thank God I'm better.

Interviewer: Before you have a seizure you said your head gets heavy …?

Participant: Yes, I get so down I want to cry.

Interviewer: Do you think there's anything that makes you have a seizure, a bad news or …?

Participant: Yes, with bad news I get down, and if I get down most the time I have it (seizure).

Interviewer: How do you feel after a seizure? How's your health?

Participant: I mean, for a week I feel like I've walked the mountains, my whole body is stiff, my body aches, I've always got a headache, I mean I get in a really bad way.

Interviewer: How long does this last, you said a week?

Participant: For a week, after the week I get a little better, I'm not so down, day by day I get better.

Interviewer: Are you mentally tired or physically?

Participant: Mentally and physically, both, you know you get anxious thinking about it, and if your mind is anxious your body is tired.

Interviewer: What do those around you do when you have a seizure?

Participant: Those around me, most of the time, they've all cried for me, you know especially my children, my son got it because he was so worried about me, every time he saw me get like that, it used to really upset him and he would cry a lot, he would get so upset, he got it from that, but I can't bring myself to ask him to come and sit down, it's not nice for me to ask him to come so you could ask him questions.

Interviewer: Its fine, how do those around you feel when they see you have a seizure, apart from your son?

Participant: It's upsetting for all of them, if I say my brother in-law, my other brother in-laws, all of them really stressed about it.

Interviewer: Apart from your medication, do you feel you have any control over your seizures?

Participant: You know now I've made myself be in charge of myself so I don't think about it so much so I don't stress about it so much, I want to be control of it, up to now, I'm mentally more comfortable than before.

Interviewer: At the beginning when they told you you had epilepsy, how did you begin to accept it?

Participant: I took it very normally, it still upset me, it upset me because it's not a nice thing, it's for a long time, and when I went to the doctor he said because I got it from an accident I will get better, he said 'when she gets better and sees her children, she'll be happy with her home and children, she would generally pass the illness.'

Interviewer: But it didn't pass?

Participant: No it didn't pass

Interviewer: Do you think it's understanding the illness that made you accept it or was it something else?

Participant: Well mentally, I got happy with God and said 'God I'm depending on you I've now got this I have to tolerate it', until God sends me protection, I have to be in charge of myself, be happy with myself and I can't let it get to me so I don't get worse, and get other illnesses, I tried to control it rather than the illness controlling me.

Interviewer: Do you think you can tell people you have epilepsy?

Participant: Yes it's fine.

Interviewer: Do you think your life has changed because of epilepsy?

Participant: Up to a point it has affected me, most of the time it has been ok because I've thought its God given illness, God has sent it to me so it's been ok.

Interviewer: Has it hindered anything in your life?

Participant: Yes, it has

Interviewer: Like what?

Participant: Sometimes, if I wanted to go somewhere, to travel, if I got ill health, if I wanted to go somewhere, for a picnic, for a visit, to go out, if I got ill health I couldn't go even if I had got changed, I changed back saying 'it's better I don't go', most of the time I've gone and on the way I got it (seizure), those things are really upsetting.

Interviewer: Do you think, your views, for your life has changed because you have epilepsy? Or be more wary or more careful?

Participant: Yes, I've wanted to take more care of myself, its always been in my mind that 'I've got this illness I have to take care of myself'

Interviewer: Do you think people treat you differently if they know you have epilepsy?

Participant: Yes many people, some people look at you in a way that's upsetting

Interviewer: Like what?

Participant: Like this illness, they've said 'oh poor you, you have this illness' they have treated me different to a point.

Interviewer: Less or with pity?

Participant: Many people, it's our manner and community, some people with pity and many people think of it in a different way, our community has all sorts.

Interviewer: How is it looked it in the Kurdish community, if someone has epilepsy, how is it looked at or spoken about?

Participant: It's up to the person, some people have pity, some people see it differently, they say 'well, so and so is ill, maybe they're bad that's why God has given them this illness', many people with pity, they say 'God is showing them his love, you get everything in life.'

Interviewer: Do you have anything else you want to talk about that may be important to you or important for the illness?

Participant: No I have nothing else, but I pray God helps all those who are ill.

Interviewer: Those who are newly diagnosed, how would you advise them?

Participant: I would tell them ‘God is great, people have to make themselves happy and have to be in control of themselves, not think about it too much.’ I mean if you think too much about any illness it becomes more dominant but if you can be more dominate its better.

Interviewer: Thank you very much.

Participant: It’s no problem, you’re welcome.

End of interview

13.19. Kurdistan Participant 9

Kurdistan Interview 9 M

Interviewer: How old are you?

Participant: I'm 42 years now

Interviewer: You're married?

Participant: Yes

Interviewer: How many children do you have?

Participant: 3

Interviewer: What is your occupation?

Participant: I'm a worker in an office

Interviewer: What is it you do?

Participant: I'm a guard

Interviewer: How many years have you had had epilepsy?

Participant: Err about 3-4 years

Interviewer: Do you know anyone else who has epilepsy?

Participant: Yes

Interviewer: Who?

Participant: My wife has it, err my friends but I don't remember their names t the moment

Interviewer: When you were diagnose with epilepsy, what happened?

Participant: With me it was thinking, I used to think a lot, the time I got epilepsy.

Interviewer: Was it a problem that arose?

Participant: There was a problem, I thought about it a lot, it affected my head and I got this issue, I got this epilepsy, err then they took me to the doctor and the doctor gave me treatment, the treatment bit by bit …

Interviewer: How did you feel when they first told you you had epilepsy?

Participant: It was normal but after the thinking gets more and then I was young and it really affects you when you're younger.

Interviewer: Did you have knowledge on epilepsy before you got diagnosed?

Participant: I had a bit but not much

Interviewer: What about afterwards, did you have more knowledge?

Participant: Just the information the doctor gives you, what epilepsy is and isn't

Interviewer: How do you mean? How much did they explain?

Participant: I don't know exactly, I don't remember now, how it was, it's just that they explained the description of the movements, what happens to you, sometimes you bite your tongue or bite your lips, or your eyes roll over or you foam at the mouth, they would explain these things.

Interviewer: How did your family and friends help you when…?

Participant: They were good.

Interviewer: What did they do for you?

Participant: When I used to get those incidents they would hold my arms, hold my legs so I didn't hurt myself.

Interviewer: Would they talk to you to make you feel better?

Participant: Yes, they would, when I got up they would say 'it's nothing, it's very ordinary, this illness', they did so it didn't affect me.

Interviewer: How do you feel before your seizures? Do you feel anything, what are the symptoms?

Participant: I would get upset, I would get a headache, like an electrical impulse, in those times I would, but I would lie down, I would sense it and after about 15 to 20 seconds I would get the incident, I would hear their conversations but I couldn't reply

Interviewer: What about afterwards, when the seizure subsided and you were awake?

Participant: I was normal, but my body ached, like you say ache, then after that sometimes they'd massage me and sometimes I would tell them to leave me alone so I get better myself.

Interviewer: What did those feel around you when they saw you have a seizure?

Participant: They were upset about it.

Interviewer: What sort, pity?

Participant: Pity, the pity aspect was more, they were upset with the situation that was becoming of you

Interviewer: Do you think you have any control over your seizures, without taking tablets?

Participant: Yes, now I think less, because the doctor says the first thing is thinking, when you think you get like that, now I do that, I think less so I can manage the situation, manage the illness.

Interviewer: When they told you you had epilepsy, how did you manage to accept the illness? To accept the illness and not let it affect you that much, was it understanding the illness, or family?

Participant: The doctor told me, from the minute I went to see him, he sat me down, he advised me for about 2-3 hours.

Interviewer: How?

Participant: He explained about the illness, what those situations are like, you have to prevent yourself for example in water, in a high place, you can't go to dangerous places, secondly thinking, you can't at all, what happens to others you can't think about it, think about yourself, your mental state so your head rests and so the situation can pass.

Interviewer: Do you think you can tell people you have epilepsy?

Participant: It's very ordinary, the reason I tell them is because so they know, when it happens to me they can help

Interviewer: Do you think your life changed because of your epilepsy? Do you think you felt you had to change your life, your views?

Participant: Of course

Interviewer: Like what?

Participant: You change your life because you have this situation, there are some things you can't do.

Interviewer: Like what?

Participant: Like work, you don't have the energy to work, there are some jobs you can't do, for example driving, like somewhere dangerous you can't go.

Interviewer: Did this affect you, these decisions to stop yourself from doing?

Participant: Yes

Interviewer: How did it affect you, for example, how did it affect your views for your life for your family? Or when you couldn't drive somewhere or to take part in a social situation?

Participant: That affects you, there are some places you want to go but you can't because you can't drive, you have to ask someone else to pick you up or there are some other duties you can't do you have to ask someone else to do it, that affects you.

Interviewer: If people knew you had epilepsy, would they look at you differently? How would it be?

Participant: Those around me were fine, they would help me and not to hurt me or make fun of me, they didn't have with me.

Interviewer: How is epilepsy looked at in the Kurdish community?

Participant: There are some people that look at it as a bad thing and there are some people normally and help that person.

Interviewer: How do you mean bad?

Participant: The bad thing is they make fun of the person, they say 'you are like crazy' or make fun of that person and make the person experience the situation, they have that, some people are like that.

Interviewer: Have you experienced things like that?

Participant: No, those people I would be involved with were not those kinds of people

Interviewer: What's the most difficult thing for someone like yourself who has epilepsy that affects your life?

Participant: How do you mean?

Interviewer: For example in regards to family, friendship, work, if someone has epilepsy, what's the most difficult thing for them for their life?

Participant: Everything as far as that person is concerned is difficult, when you have that condition you can't do anything.

Interviewer: If you know someone who has been told recently they have epilepsy, how would you advise them?

Participant: My advice would be when they tell them not to be upset, don't think about it, on the contrary think about managing themselves so the condition gets better bit by bit and be rid of it quickly, they more they think about it, they more they get deeper with the illness, the illness would dominate they wouldn't get away from it easily, they would have it forever.

Interviewer: Do you see the condition as a temporary or something that's ongoing for life?

Participant: Temporary, I see it as temporary

Interviewer: Is there anything else for you to talk about, so it benefits this condition or for those people with the illness?

Participant: I don't know how to talk about it.

Interviewer: Information…?

Participant: The information is just that if someone gets it not to think about it, look at as a simple thing, so it doesn't affect their brain even more, the more they think about it it affects their brain, it may make them mad.

Interviewer: Do you think it's having knowledge about the illness itself or believing in God that helps you accept it, or help from your family?

Participant: God is on top of everything, healing is in his hands, help from your family is essential, that's the second level that helps you, the first is God the second is you family and those around you.

Interviewer: Thank you very much

Participant: No problem

End of interview

13.20. Kurdistan Participant 10

Kurdistan Interview 10 M

Interviewer: How old are you?

Participant: I'm 18 years old

Interviewer: Are you married?

Participant: No

Interviewer: And you have no children?

Participant: No

Interviewer: What is your occupation?

Participant: I'm a student

Interviewer: A student, what level?

Participant: In year 11

Interviewer: How many years since you've had epilepsy?

Participant: About 2 to 2 and a half, 3 years

Interviewer: Do you know other people that have it, friends?

Participant: No

Interviewer: Tell me about when you were first diagnosed?

Participant: Yes, as far as I remember it was a night, we were sitting, I was watching television, I felt my body starting to get stiff, my arms and legs were still, but at first when I would get it I was aware, just my arms and legs would get stiff but gradually I would get like that and lose consciousness, I would have a seizure, we went to Iran and there, I think we went twice or three times, the doctor gave me tablets and said to take them and come back every 6 months, when I would take the tablets I was a lot worse at nights and my seizures increased, so I thought I best leave it (not take the medication anymore), the last time I went back to the doctor I said I'm worse and at nights it hurts me more, first I did a brain investigation (EEG) he said a vein in your brain is blocked or something else, I said ok, then I felt, because I was aware when I got like that, my heart was beating faster, I mean I would struggle for breath, we went to a heart doctor. When we went to see him he did an heart investigation (ECG) he said 'your heart ventricle is loose, it's because of that it makes you feel like that' we said ok, then he gave me a tablet, when I took the tablet I couldn't sleep because of the pain, then I told my dad, I said 'dad let me not take the tablets for a while', when I didn't take it, on the sly, I could sleep at night, but they kept saying take it you might get better, maybe the pain is that you will pass it (epilepsy), I said ok. I took it properly for a while, but gradually I was getting worse. I would get like that (have a seizure) 2 or 3 times in one day. When we went back to Iran I told the doctor, he said 'you're lying, I prescribed you tablets you have to take it properly', I said 'why would I lie about my own illness?' we bought the tablets but I still haven't taken it. This year I have had it twice, twice, thank God I haven't had it since.

Interviewer: You don't take tablets?

Participant: I don't even take tablets.

Interviewer: How did you feel when they first told you you had epilepsy?

Participant: I was really upset at the beginning.

Interviewer: Why mostly?

Participant: You feel inadequate when you get like that.

Interviewer: Compared to those your age?

Participant: Compared to other people, compared to that you're ill and you look around you, they worry, get upset and you are mentally uneasy.

Interviewer: Did you have any information on epilepsy before you got like that?

Participant: My mum had it, my mum had it, and they were talking about my dad had it but my grandmother, I think she passed away in '99, I remember my dad had a seizure in her funeral, my mum, up until last year still had seizures, but I haven't seen my dad have a seizure since '99.

Interviewer: When they told you you had epilepsy, how did your family and friends help you?

Participant: They helped me a lot, they would tell me not to worry there's no need, everyone gets ill, you have to be grateful to God, there's no need, you'll get better, bit by bit, it was only a year, now I just joke about it. It's like it's not even there, I don't even think about it.

Interviewer: Do you think there's anything that causes you to have a seizure?

Participant: Up until now I haven't noticed anything but once I felt when I get really hot I get like that, a lot.

Interviewer: When it's really hot?

Participant: A lot, I think.

Interviewer: How do you feel after a seizure?

Participant: After a seizure, after a seizure my body gets stiff, my body aches, but its only 10 to 15 minutes, because I don't worry about it I get up straight away.

Interviewer: What about those around you, how do they feel when they see you have a seizure?

Participant: It upsets them, it upsets them a lot, but what can we do, there's nothing we can do.

Interviewer: What do those around you do when you have a seizure? How do they help you?

Participant: During a seizure, because I'm not aware, I don't know how I'm helped but when I get up they all gather around me, 'get up, it's nothing, you'll get better', they make me feel better.

Interviewer: Do you like it, when people around you talking to you?

Participant: I like it, yes, you're comfortable

Interviewer: When they told you you had epilepsy and had to take medication, how did you accept this illness? What helped you accept it?

Participant: First of all, if you don't accept it, what are you going to do? Secondly, because your mum and dad tell you to take tablets, they feel better otherwise I never want to take one pill, I don't like it, but because of your mum and dad you have to say I'll take it and maybe they'll feel better.

Interviewer: Do you think you've accepted it and got used to it?

Participant: Believe me I don't even think about it.

Interviewer: Can you tell those around you you have epilepsy? Friends

Participant: Its fine, but if I know it upsets them I would never tell them and I would never repeat it.

Interviewer: Get upset because of you?

Participant: Of course it upsets him because of me.

Interviewer: Do you think your life has changed because of epilepsy?

Participant: No, I don't feel anything.

Interviewer: Has it affected your outlook on your life?

Participant: You mean think like it ruins my life and things like that?

Interviewer: Yes

Participant: No, because I'm saying I don't think about it, nothing, whether it's here or not.

Interviewer: Do you think people would look at you differently if they know you have epilepsy or if they see you have a seizure?

Participant: No, they just try and make me feel better if I talk about it, and if I don't talk about it they won't talk about it.

Interviewer: Do you think there's anything you can't do because of epilepsy, fearful of something or driving?

Participant: Before I get it, I think about it, I go and get busy with something else so I don't think about it and if I don't think about it I go and go where I like.

Interviewer: How is epilepsy looked at in the Kurdish culture?

Participant: If I say it's looked at as a big thing it's no lie, and if I say something small it's not true.

Interviewer: How?

Participant: When you talk about epilepsy, they think it's strange, they think it's strange, they say 'he seizure, this is like that, and he gets like that', I don't know how to talk about it, but I'm sure they think it strange it when you talk about epilepsy.

Interviewer: Why strange?

Participant: Epilepsy, I don't know, you're not aware, I punch, I kick, and they think it's strange, do you understand? And it's something that there's not a lot of in Kurds, but what can we say?

Interviewer: What's the most difficult aspect of having epilepsy? The most difficult effect it has on your life

Participant: It doesn't

Interviewer: It doesn't? Do you think it will in the future?

Participant: I don't think so, I haven't got to that kind of thinking of it having an effect.

Interviewer: What about those who have just found out they have epilepsy, what advice would you give them?

Participant: I would say never think about it, never, there's no need to think about it, because the year I was thinking about it, in a day would have it 3 times, 4 times, but when I gradually made myself comfortable and said I'm not going to think about it, I won't take tablets, I gradually got better. Since not thinking about it, I've had it twice since last year.

Interviewer: What change would you advice so they don't think about it, so they can accept it and live with it, and make their life easier?

Participant: It has to be accepted, it has to be accepted, what are we going to do if we don't accept it?

Interviewer: What helps you accept it, understanding the illness …?

Participant: You have to be dominant over the illness not the illness over you and keep getting it and getting it. It's better to be dominant over it then to get it more and it becoming dominant on you.

Interviewer: Do you have anything else you want to talk about it, or important for this topic?

Participant: Just that, I say don't think about it, there's no need because it's not in our power, the more you're dominant over it is good, and as much as you can I say don't take tablets. I don't believe it, I don't know.

Interviewer: Nothing?

Participant: Nothing

Interviewer: So you're more dominant over your illness?

Participant: Thank God, I'm dominant, I won't let it come near me at all.

Interviewer: Thank you very much

Participant: No problem, if you need anything else, I'm prepared to help.

Interviewer: Thank you.

End of interview

Chapter 14: Qualitative Study (1) Participant Characteristics

14.1. Kurdistan Participants

14.1.1. Participant 1

The first participant to be interviewed in Kurdistan, Northern Iraq, was a 24 year old female. She had a temporary position while waiting for a permanent job offer as organised for graduates from the local government. She had been recently wed to her husband. She had been diagnosed with epilepsy since the age of 16. This participant was particularly interesting as it can be understood from the information below, she had a very strong connection to epilepsy and its effects on her family. Her eldest brother had epilepsy but refused to admit it, and one of her other brothers had such severe epilepsy, which was uncontrolled that he had committed suicide soon after graduating from university only a few years earlier. I came across this information after the interview when her family wanted to know more about what I was doing with my research, however, this participant was not particularly worried about having epilepsy herself and wanted to ensure that she could control her seizures so she could have children safely one day. This participant had been prescribed medication but seeking a medication that didn't harm her baby during pregnancy. Her husband was very understanding of her epilepsy, he took time out to talk to me after her interview, this is very unusual as the culture is very restrictive on how it views epilepsy, as it can be seen from the data transcripts. For an unwed person to find a marriage partner when it is known they have epilepsy is extremely difficult. This interview was carried out in the participant's mother's house.

14.1.2. Participant 2

The second participant was a 30 year old young man, he had been suffering with epilepsy since the age of 11. He was a teacher and led a normal life. He had very severe seizures which were not controlled. He had only had a seizure a few hours earlier from our interview but was happy to talk to me and be very open about his experiences. He felt he wasn't able to start a relationship/marriage because of his condition and the judgements made by people. He felt very strongly about this and mentioned it a few times. He could understand the severity of his condition and felt quite helpless towards it. I have to admit that I was particularly aware of the situation, any stress could have triggered his seizures and felt I was extra sensitive during questioning by allowing him to talk freely on the topics important to him, such as marriage and still managed to ask my own questions to ensure the consistency of the data. This interview was carried out in the participant’s home.

14.1.3. Participant 3

This participant was a 36 year old man, who was a porter in an import/export warehouse. During the interview he kept insisting that he did not have seizures anymore but was still on medication, however, after the interview his wife sent me a message to say that he continually has seizures but refuses to acknowledge them. This interview was particularly tricky as the participant, although signed the consent form and was happy to take part, did not seem to want to give too much detail regarding his condition and kept insisting that he was fine. This interview took place in the participant’s place of work in the office.

14.1.4. Participant 4

This participant was a 43 year old married woman, with three children. She had been diagnosed with epilepsy for about 12 years, soon after getting married. She was very open minded about her condition but quite tired with her seizures as they made her very vulnerable and had to take a leave of absence from her office job for a year until her condition becomes stabilised. This interview took place in a room in the hospital where the EEG takes place.

14.1.5. Participant 5

This participant was a 21 year old male student. He had been diagnosed with epilepsy first at the age of 6, the condition then improved and returned at the age of 12. This participant was very adamant that he didn’t want people to know and kept it from all his friends but one. This interview was carried out in the hospital in a secluded place in the garden.

14.1.6. Participant 6

This participant was a 38 year old married woman, who was a housewife and had 6 daughters. This interview took place in the hospital room, where the EEG is carried out. Epilepsy was an issue for this lady as she felt that people around her were mocking her as she had epilepsy and didn’t have a son, which seemed to have become an issue for her. She was quite desperate for a cure. Not only to have fewer seizures and have fewer severe symptoms of epilepsy but also to try and get pregnant hoping for a baby boy to avert rumours of his husband wanting to remarry.

14.1.7. Participant 7

Participant number 7 was a married 25 year old woman who had 2 children, one of whom was only a few weeks old. This interview took place in the home of her in-laws where she had come as her husband was at work and she was not to be alone in case she experienced a seizure. She had started to have seizures only weeks into her marriage. Epilepsy seemed to have affected her quite badly, throughout the interview, she was quite teary, she had left education when her seizures became frequent, and wasn’t confident enough to travel on her own or be on her own at home with the children in case she has a sudden seizure. This lady seemed very fragile and epilepsy had taken over her life but didn’t believe in taking medication as she didn’t think they would help her.

14.1.8. Participant 8

This interview was carried out in the participant’s home, she was a 44 year old woman who had 3 children and was a housewife. She had been diagnosed for over 25 years. This lady was confident in herself, but was more worried of the effects of her seizures on her children. She told me she had been seizure free for a while, although she didn’t specify how long. A few months after the interview, I was made aware through a friend of her family that her seizures had returned quite severely, although I am unsure of the circumstances. This lady was open about her condition and wouldn’t hesitate to tell others of her condition.

14.1.9. Participant 9

Was a 42 year old man, he was a security guard for an office. The interview took place in the home of the participant. This participant was comfortable to talk about epilepsy and its effects, and he explained to me he had been diagnosed 3-4 years.

14.1.10. Participant 10

This last participant was an 18 year old young man who was a student, the interview took place at his home. He had been diagnosed less than 3 years. During the interview I felt that he wanted to convey that he didn't really care about his condition but he seemed to protest quite a lot that he did not give epilepsy any thought and wasn't very forthcoming about the effects of his condition.

14.2. UK Participants

14.2.1. Participant 1

The first UK interview was carried out in the home of the participant, she was a 27 year old lady, and she had 2 children, the youngest two months old. She was cohabiting with her partner. She had been diagnosed with epilepsy for about 10 years and didn't feel that it had affected her life much. She was quite knowledgeable about her condition and felt comfortable to speak freely. She was on medication and was aware of steps she needed to ensure her well being and reducing her chances of having seizures. This participant seemed comfortable during the recorded session and continued drinking her tea while talking about epilepsy and its effects on her life.

14.2.2. Participant 2

The second participant was a 48 year old lady who had 3 children, she was married and had been diagnosed with epilepsy for 18 months. The interview took place at one of her friend's house. This lady been had been signed off work for 6 months for investigation into her condition. This lady was knowledgeable about her condition through working with an epilepsy organisation. She volunteered with the charity to help others and accepted her diagnosis but felt others in here family were quite worried about her and she was more worried for them.

14.2.3. Participant 3

This interview took place in the participant's home. She was a lady of 70 years of age, she was divorced and living on her own. She had been diagnosed with epilepsy for 63 years. She had made it her job to be very knowledgeable about her condition and was an active volunteer with a charity to help people with epilepsy.

14.2.4. Participant 4

This interview took place at an epilepsy conference, in an outdoor area on the terrace. The participant was a 41 year old man, who was originally from Belfast in Ireland, he was married 14 years and with no children. He was an accredited volunteer with the epilepsy organisation and seemed comfortable in himself. He had epilepsy since the age of 13, although he was seizure free for some years before its return in his 20s.

14.2.5. Participant 5

This participant was a 44 year old single lady who was originally from Finland and had been a UK resident for over 15 years. She had been diagnosed with epilepsy for 35 years, although her seizure type had changed from absent seizures to more severe seizures where she loses consciousness. She was currently volunteering and had also taken part in the Olympics as a volunteer. This lady seemed to have accepted her condition but was very disappointed in herself for not being in paid employment and seemed generally down on herself during the interview

14.2.6. Participant 6

This participant was a 58 year old lady whom I met at the epilepsy conference, she described herself as medically retarded, which she didn’t explain further. She had cerebral palsy and had epilepsy diagnosis for 26 years. On the outset I felt that the interview may not be of much use to me and not be relevant, however, I was proved wrong quite quickly, she seemed in tune with her condition and was very independent. During the interview this participant coughed quite violently and I briefly left the table to get her a glass of water and the interview continued.

14.2.7. Participant 7

This participant was a young man who was 26 years old and had been diagnosed with epilepsy for 10 years. He was working in IT but was very conscious that he wouldn’t tell his work managers about his epilepsy in fear of losing his job. He seemed to understand the condition but was quite fearful of the stigma attached to epilepsy. He felt that companies didn't differentiate between the types of seizures and were cautious with anyone with the condition. He wasn't very forthcoming with his experiences of epilepsy.

14.2.8. Participant 8

This participant was a 46 year old single female and she had been diagnosed with epilepsy for 7 years, she was originally from Iraq but had been a UK resident for over 20 years. This participant was in full time employment as a PA. This lady was very detailed in her description of her experiences and was a joy to speak with and was at peace with her diagnosis but felt pressure from her family to keep her condition secret as they were from a different cultural background. This was her first epilepsy awareness conference and she was very relieved that she could meet other people that she could relate to and was also very eager to speak to me and approached the stand, where I was based in the event, several times to express her interest to speak to me, as the organisers had let attendees know of my research interests.

14.2.9. Participant 9

This participant was a 21 year old young lady. She looked very young for her age so when she expressed interest to take part in this study I found myself asking for her age before going to the interview area. Her epilepsy diagnosis had been from birth, she had experienced quite a lot of bullying when growing up and seemed quite sheltered and stayed by her mum's side at all times except for the period of this interview. At the end of the interview she did ask me if there was a cure but as I am not an expert in the field or medically trained I informed her that she would need to speak to her specialist about that, I felt that her participation was mainly of hope of information for a cure.

14.2.10. Participant 10

This participant was a 66 year old man, who had been diagnosed with epilepsy for over 50 years, he was a civil servant, married and had two children. This gentleman was very knowledgeable about his condition but felt that epilepsy had not held him back and was very eager to share all his experiences about epilepsy, even when not asked, for example, employment difficulties for people with epilepsy. He had a managerial position with the epilepsy charity and seemed like a very positive person generally.

Chapter 15: Interview: Dr. Jamal Omar

Doctor, thank you for agreeing to talk to me. Please state your name just for the record.

Yes I am Dr Jamal Omar, err Psychiatrist, Specialist Psychiatrist, the Head of Psychiatrists in Sulaymaniyah and I'm working for more than 35 years as a Neuropsychiatrist because in the past there was no neurologist, no neurosurgeon so I have a long experience with those patients with convulsion. Even the psychological or we call it convulsion disorder also they come in like that, err epileptic fit sometime, although it is different clinically. The problem of the I think most of the people have one seizure in their life, possibly 2 seizure or sometime they are no noticed by other people or even by himself or even his relative, possibility of it occur whilst sleeping, 3 o'clock, 4 o'clock or midnight, or after midnight. Err the problem of the convulsion or the err all the type of the seizure or all the type of the convulsion; it will affect the psychology of the patient. Although minority, very minority of them they will not control so really they become disable, they cannot work they cannot even take care of himself because most of the drugs we are using, I meant anti convulsive they are resistant to him, err the other problem of this type of disease err is that associating with psychosis, so psychosis is associated with epilepsy, and that type it can be more complicated err other which is also I mention sometime the epilepsy is associated with convulsion, this mean affects the psychology o I saw him, sometimes we see one fit during years but we see many, many, many episode of conversion during months so this mean that this patient feel, especially in the young female, like she is not like other people, or possible she had bad future or she is very pessimistic about her future, overall the main problem here is that we have no, a good system to deal with these people.

What sort of system do you mean?

I mean a system that, or a policy, so some of that physician or call him neurologist they will possible from begin of the simple fit begin with a new generation of anti-convulsive, the problem of the new generation of anti-convulsive is that it's not always available and secondly it's expensive especially for those who have a low income that they cannot, although the government or the health system, government health system or health service will provide them with the drugs but not always the genuine or the mother company. So this is err, and also as I told you we have no this protocol, it is not system I mean protocol, this protocol if it is applied he cannot apply it, why because we have the service here we have a private service and also we have the err government service, I mean sometime we mix it between these two, there is no separation between them, so this is a big problem which is we are facing in Iraq as a whole not only in Kurdistan. Although many times they are trying, they're improving the health system, but still because it is related to the political situation related to the mentality of the people, related to the administration etcetera.

You mentioned that it's difficult especially for you women to deal with the psychological symptoms, why do you think that is, and what sort of psychological symptoms do they experience?

You know err although it's not a critical disease but it will sort of a tragedy that someone see a girl, a young girl with a fit, that time the patient injure himself or sometime wet himself or a sort of a tragedy that all the surrounding affect her you feel sympathy for her, so in this sort of sympathy, this sort of fit affect the psyche of them that it feels the inferiority complex. It will, most of them, it will have.

Will it affect them any other way in their life?

Yeah

How so?

Yes there are, if it continuous if it is not controlled and also the surrounding of the people with him all the family are always consider him as not like a normal person and also you must take care of him, if he, she have a fit outside on the street and it is possible it is like sort of like, I'm not say it like a shame it is sort of psychological reaction for the err family so they will try to keep them at home.

All the time?

Yes most of the time, even in, even most of them also left school because they will have a fit in front of the other students, in front of other pupils so err they feel pity or they feel something that he is abnormal or she is disabled, this is what we see.

Before we started recording you mentioned stigma, how do you think that is related to culture?

You know, you know all of the psychology all of the mental disorder, I'm sure even in the West country there is always stigma, definitely there is stigma, although we are struggling to decrease, struggling against stigma but still is there, stigma. Here is more, because here the people are the life is not individual, their life is social, the people are interfering with each other, not like, this is the two style between the East and between the West, the people id always monitoring.

Right, so how would you describe a normal family life in this culture?

What you mean by it?

Is it more obligatory because of family life and neighbours?

Yes and also this other problem, I forgot to mention this, the problem of marriage and epilepsy.

Yes please say.

So many people is coming as I told you is family you know the err the marriage here is different to marriage, even the marriage here is like family planning, arrangement by the family, so that's mean mixing between two family not relation between two persons, between two possible big families, they will come if they tell the one who come to for engagement or for other, they say it shall we just tell him that she's ill or not?

What is your advice?

That's the problem, that's the problem but my advice is to tell them the truth but here when they tell them the truth so the man withdraw, withdraw soon, because say I will not become a victim and also I spend all my life with this but we tell him that this 85% you will be cured, 85% and 50% will be remain and also accordingly we have according to the case, you know it, this is not a general tell. So it’s a bit complicated and also they ask us so if they are married and they become pregnant shall we take also the pills? I say this anti convulsive also affect the baby, so we tell them, we tell him that the medicine will progress and there I a possibility of a discovery of a new also now, some of the new anti-convulsive will have less effect on the baby or the infant or the foetus. So whatever be the life of these people also is not an ordinary life, not living as normal circumstances.

Would you say that applies to the male and female population?

Of course the female as you know have no rights but for the male it’s not so difficult, it’s possible if he tries to marry someone possibility they may refuse otherwise ordinary there is no refuse.

So would you say with a person who has been diagnosed with epilepsy, this takes over their life completely?

Yeah

And affect everything?

Definitely, schooling, affecting the job, affecting the relation, affecting everything, even the male, not only the female, even the male. When they found it’s sometime, sometime, there is a period that it will always, almost there is continuous fit, so at that time they restrict their patient and they don’t him to go outside or if they go outside they have to be accompanied by someone and the other thing is the other people in the culture the drugs is no good, if you are taking for a long time it is possible be used to this that (inaudible recording). So it is a bit complicated like, it is although we consider them as a neurological disorder, epilepsy, but at the same time it is strongly relations with psychiatry and psychology.

What sort of psychiatric disorders will they develop as a result of epilepsy?

As I told you conversion disorder, conversion, it’s very common among these, psychosis, it is a real psychosis, they become psychotic patient, isolation, abnormal behaviour, attacking the people etcetera.

Also in your 35 years of service have you seen any changes in the patients, in how you deal with them, culturally?

Yes, you know err it is different the people is progress, it's better.

How so?

Progress, their mentality is better and they are accepting the disease, it's better than, but still, still they consider it a sort of stigma, and also the diagnosis is better although we are depending on the diagnosis on the witness of fit, if there is someone is with him it's possible, because we do EEG and even EEG will find very, but 55% will have no change in the EEG so the witness or the clinical diagnosis for us is still there at the top, we do, in the past we have EEG but not have easy access so it was, possible (inaudible) capital of Iraq, now it is easy, we continuously monitor the patient. Also other like the CT scan or MRI was not available in the past but now it is available also because sometime the cause of epilepsy sometime we call secondary cause because there is a tumour, there is a cyst, there is what's called the chronic (inaudible) infarction etcetra. So it is now easier for diagnosis, we tell the patient it is either idiopathy or secondary, in the past we has no access to this.

Do you think it's more difficult to accept because it's been seen as a psychiatric disorder or a neurological, do you think it's easier to accept if it's one or the other?

I think it's not so different. In the you know most of the case come in the child period, they're coming in infancy, child, they are going to the paediatrician and the paediatrician will diagnose and follow the case until the age of 12 or according to the wish of the family, possibly go with a child paediatric doctor until it become (inaudible).

And do you think it matters how they've been …?

We tell the patient the truth from the beginning, if there is proof this is a typical epilepsy or it whatever kind, partial epilepsy, whatever we tell them this is the disease coming and going, it is chronic and it is best to take the medication regularly for at least four years, at least, at least we tell him four years then after that we see if it needs more or if it possibly cease or stop by itself.

Is there anything else that’s important for me to know about the culture …?

I think I talk too much.

Thank you very much.

End of interview

Chapter 16: Kurdish History

It was during the battle of Chaldiran in 1514 that Kurdistan was first split between the Ottoman (Turkey) and Persian Empire (Iran) (Meho & Maglaughlin, 2001). The Ottoman Kurdistan was further divided by the British and French between Syria, Turkey and Iraq in 1920-1923 (Meho & Maglaughlin, 2001). Social and economic disregard for Kurds by central governments have forced Kurds to become nationalists thereby not embracing state oppression (Meho & Maglaughlin, 2001). It is estimated that there are 30 million Kurds and a third of that figure live outside of Kurdistan due to war, compulsory resettlements or economic instability (Meho & Maglaughlin, 2001). This number makes it the largest nation without an independent state (Gunter, 2004). Immigration, due to political or economic factors, has caused political and social awareness amongst the Kurds and furthermore strengthened ethnic belonging (Meho & Maglaughlin, 2001). Most Kurds are Sunni Muslims, although there are some Shi'ite Muslims, Jewish, Christians and Yezidis as well (Meho & Maglaughlin, 2001).

In 1974 Kurds went to war with the Iraqi central government over the forcing out of Kurdish families and replacing them with Arab civilians in oil rich regions such as Kirkuk, Khanaqin and Sinjar (van Bruinessen, 2007). As a result of this war, Iraqi government instigated the *scorched earth policy* where Kurdish guerrilla fighters (Peshmergas) were cut off from neighbouring countries to prevent them escaping or gaining access to necessary supplies (van Bruinessen, 2007). These areas were forbidden zones (van Bruinessen, 2007). The villages in these areas were burnt down and residents were resettled in camps (van Bruinessen, 2007). War continued throughout the 1980's and it was in 1988 that *Anfal* took place, which was the killing of Iraqi Kurds on a mass scale (Black, 1993; Chaliand, 1993). During Anfal, village civilians were abducted and their homes burned down, their livelihoods sabotaged to prevent residents from returning (van Bruinessen, 2007). The men and women were separated (van Bruinessen, 2007). The women deserted and the men were killed and buried in mass graves in southern Iraq (van Bruinessen, 2007). It was also in 1988 that the Iraqi Kurds were chemically bombed by the central government killing thousands (Black, 1993; O'Leary, 2002).

Since the early 1990s, Kurdistan in northern Iraq has been functioning independently from Iraqi central government under Kurdistan Regional Government (KRG) (O'Leary, 2002). From the mid 1990's, however, civil war broke out between the two main Kurdish parties in Iraqi Kurdistan (O'Leary, 2002; Gunter, 2004). The Kurdish Democratic Party (KDP) and Patriotic Union of Kurdistan (PUK) continued their war for a number of years (1994-1998) consequently leading the area to be split in power between the two forces (O'Leary, 2002). The two main parties (KDP & PUK) now have equal power in the running of Kurdistan (O'Leary, 2002). This area in the Middle-East was more settled politically and was beginning to join the platform with regards to developments and advancements in technology until recent events. Kurdistan was going through many social and political changes until recent events with Islamic State in Iraq and Syria (ISIS) terrorist group broke out in July 2014. This has not only halted developments in the region but regressed to the point where even basic needs are not being met.

There are many disadvantages of war and trauma. It is reported that symptoms of mental illness such as post-traumatic stress disorder, depression, anxiety and poor physical health are associated with children exposed to or affected by mass violence (Srinivasa Murthy, 2007) such as that in Kurdistan. A study of refugees of Iraqi Kurds in Sweden indicated that political instability has a great effect on people (Søndergaard, Ekblad, & Theorell, 2001). It is further reported that the existence of post-traumatic stress disorder was present among the participants in the study (Søndergaard, Ekblad, & Theorell, 2001). Additionally, research has indicated that females are more likely to meet post-traumatic stress disorder criteria than males (Tolin & Foa, 2006). However, a study carried out in Mosul in Iraq contradicts this finding and suggests that post-traumatic stress disorder is more prevalent in males than females (Al-Jawadi & Abdul-Rhman, 2007). It is further proposed that the prevalence of mental illness in children (aged 1-15) in war torn Mosul is more than 37% of the sampled population (Al-Jawadi & Abdul-Rhman, 2007).

Chapter 17: History of Epilepsy

Epilepsy as a neurological condition was not always so well understood, and history has shown that consequently those with this condition have experienced misunderstandings throughout the ages. The historical understanding of epilepsy differs greatly from modern times. According to Ancient Greek periods, epilepsy is a direct translation from the word ‘to seize’ (Jacoby, 1992). However, the earliest reference to epilepsy comes from the origins of Assyrians and Babylonians medical text books, which is in Akkadian language and was used in Mesopotamia (present day Iraq) around 2000BC (Eadie, 1995; Magiorkinis, Sidiropoulou, & Diamantis, 2010). The *Sakkiku*, translated as ‘falling of sickness’ which is understood to be epilepsy (Eadie, 1995). The text in Akkadian demonstrates a person during a seizure as the head turning to the left, hands and arms stiffening, eyes widening and frothing at the mouth (Tomkin, 1994). The description of an epileptic seizure was associated with being in a spiritual condition and under the influence of the moon God and was associated with sin, *antasubbû* (Temkin, 1994; Eadie, 1995; Magiorkinis et al., 2010). This description indicates that there were misconceptions attached to this condition even in the early interpretations of epilepsy.

The Babylonian period around 1067–1046 BC associated the seizures to evil possession and treatment was through spirituality (Masia & Devinsky, 2000). The details of epilepsy as a condition had more depth in that the explanation of what is now known as ‘aura’ was given as a heightened sense of smell, taste or hallucinations (Fales, 2009).

As well as being associated with spiritual possession, the Greeks suggested that epilepsy was also a sign of being a genius and fittingly named it the ‘sacred disease’ (Jacoby, 1992; Masia & Devinsky, 2000). Hippocrates disagreed with this explanation and suggested that it was a disease that was originating from the brain and named it the ‘great disease’ (Eadie, 1995). Others have attempted to explain epilepsy throughout the ages, but it was Hippocrates theory that epilepsy was a disease which originated from the brain that stood the test of time and has not been fully disregarded.

The history of epilepsy goes back around 4000 years to the Babylonian era, considering the period in which epilepsy has been noted and known about in history, it has still not advanced to a level where it is sufficiently understood. Despite the arguments and suggestions from the medical professions the ordinary person still associates epilepsy with it being a spiritual disease (Eadie, 1995) and this has brought about many misunderstandings of the condition, especially in some areas of the developing countries (WHO, 2010). It may be this lack of knowledge about the symptoms that may have led to misconceptions surrounding epilepsy and consequently have an impact on those diagnosed with the condition. Historical understanding of epilepsy has been summarised as ignorance, superstition and stigma for 4000 years and knowledge, superstition and stigma for the past 100 years (Kale, 1997).