Quality of life issues for people with epilepsy living in the Western region of Ireland: An exploratory study

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Abstract

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This study aims to ascertain the implications of having epilepsy and explores quality of life (QOL) issues for people with epilepsy living in the Western region of Ireland. Epilepsy is the most common but treatable neurological condition and it is estimated that up to 40,000 people in Ireland have some form of epilepsy. This research was achieved by triangulation, the use of both quantitative and qualitative research methods and consisted of a focus group, questionnaires and interviews. The focus group consisted of four people with epilepsy living in the Western region of Ireland. This focus group assisted in the development of the self completion questionnaire which was distributed to people with epilepsy on the Brainwave database. The interviews consisted of two samples. The first sample consisted of four people with epilepsy living in the Western region of Ireland and the second sample consisted of five professionals working in the field of epilepsy. This research was an exploratory piece. It was guided by a number of hypotheses that emerged through a review of the literature. The guiding hypotheses in this research are confirmed. Firstly, quality of life issues for people with epilepsy are under-researched in Ireland. Secondly, there are real physical, social and psychological impacts for people living with epilepsy. Thirdly, epilepsy impacts on the quality of life of those living with the condition. Overall these impacts appear to be negative. However, this may be subject to the context of the individual.

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Declaration

This thesis being submitted in fulfilment of the requirements for the Master of Arts.

This is my own work except where otherwise stated and acknowledged by references.

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Glossary of Terms

AED	Anti-epileptic drug
Brainwave	the Irish Epilepsy Association
EUCARE	European Concerted Action and Research in Epilepsy
EEG	Electroencephalogram: Examines the brains electrical brainwaves
HRQOL	Health-related Quality of life
IBE	International Bureau for Epilepsy
Idiopathic Epilepsy	No known cause of epilepsy
ILAE	International League against Epilepsy
INA	Irish Neurological Association
JEC	Joint Epilepsy Council
MRI	Magnetic Resonance Imaging: Gives a detailed picture of the brain
NAI	Neurological Alliance of Ireland
NEF	Norwegian Epilepsy Association
NES	Non-epileptic Seizures (pseudo-epilepsy)
Neuron	A nerve cell
PQL	Personal Quality of Life Research
QOL	Quality of Life
SAI	Sociological Association of Ireland
SPSS	Statistical Package for the Social Sciences
SUDEP	Sudden Unexplained Death in Epilepsy
Symptomatic Epilepsy	A cause for the epilepsy has been established
WHO	World Health Organization

Introduction

Epilepsy is the most common but treatable neurological condition and it is estimated that up to 40,000 people in Ireland have some form of epilepsy. The impact of epilepsy on individuals can vary. The European White Paper on Epilepsy-Call to Action (2003:4/5) states

> Epilepsy not only presents people with health problems, people with epilepsy (and their families) have to cope on a day-to-day basis with a wide range of difficulties that affect almost every aspect of their lives. Many of these difficulties emanate from the prejudicial consequences of stigma...for many people with epilepsy, their condition remains a mystery. Physicians cannot always tell them why it developed and they may not know how best to treat it. People's lives are left fractured and disjointed, and they are unable to make sense of what is happening to them, unable to explain their condition to others and fearful of what the future might hold. There is much about epilepsy that remains to be discovered and more knowledge is needed.

Moreover, Thompson et al (1993) cited in Bishop et al (2003:226/7) suggest that

> Along with the potential physical and cognitive problems associated with seizures, epilepsy has been associated with psychological and emotional problems, social isolation, and problems concerning education, employment, family life, and leisure activities.

This suggests that a diagnosis of epilepsy can have huge implications on not just daily life but poses potential problems to all aspects of life for the individual. Over the last three decades there has been growing interest in the role of non-medical factors in treating patients. According to Jacoby (2000) the term quality of life first made an appearance in the 1970's. Quality of life assessment is an approach which unambiguously establishes the patient at the centre of attention. It is especially relevant to people with illnesses where the preservation of quality of life rather than cure may be the main goal of treatment (O'Boyle, 1997). Steinbuchel (2000:66) points out

> ...that it is a subjective concept the patient is the expert on his or her quality of life, and maintains that 'the ways in which the disorder and the seizures impact on a person's life are as individual as fingerprints'.

From reviewing current literature it became apparent that quality of life in epilepsy has been explored and researched in many other countries but to date there is little research in this area in Ireland. Therefore the researcher felt that quality of life in epilepsy warranted further exploration within an Irish context in order to provide a basis for understanding these issues.

This study identifies the implications of having epilepsy and explores quality of life issues for people with epilepsy, specifically those living in the Western region of Ireland. From this a number of objectives may be achieved. These objectives include: to highlight epilepsy as a public health priority among local and national government boards and agencies. To highlight specific quality of life impacts for people with epilepsy. To promote the exchange of knowledge between all disciplines in relation to the physical, social, and psychological impacts of epilepsy; and to highlight the need for a national database regarding the number of people with epilepsy in Ireland.

According to Camilleri-Brennan & Steele (1999) the three main domains within quality of life assessment consist of physical, social and psychological impacts. The physical domain refers to the person's ability with regard to daily activities. The social domain refers to integrating and relating to family and other members of the community. The psychological domain refers to aspects of well-being (Camilleri-Brennan & Steele, 1999). Universal quality of life impacts for people with epilepsy was also explored as part of this research. These impacts are common threads which overlap with physical, social and psychological impacts for people with epilepsy but also have implications for social and health policy. These four areas were explored during the course of this research and this was achieved by triangulation; the use of multiple research methods. People with epilepsy's consultation was sought through each of the three research methods namely, the focus group, questionnaires and the interviews. This was seen as essential given that quality of life assessment has been described as a subjective phenomenon. The quantitative methods used were a focus group and a self completion questionnaire. The focus group was conducted with people with epilepsy living in the western region of Ireland. This led to the development of a self-completion questionnaire which was distributed to adults with epilepsy who are members of Brainwave, the Irish Epilepsy Association. A number of interviews were also conducted and consisted of two samples. The first sample consisted of professionals working in the field of epilepsy. The second sample consisted of four people with epilepsy living in the Western region of Ireland. Exploring these issues will significantly increase our understanding of epilepsy while raising awareness of the key issues surrounding this condition in order to develop more adequate service provision.

This research was an exploratory piece. It was guided by a number of hypotheses that emerged through a review of the literature. The guiding hypotheses in this research were grounded by a number of theories. Firstly, quality of life issues for people with epilepsy are under-researched in Ireland. Secondly, there are real physical, social and psychological impacts for people living with epilepsy. Thirdly, epilepsy impacts on the quality of life of those living with the condition. Overall these impacts appear to be negative. However, this may be subject to the context of the individual.

Chapter two gives a detailed account of previous research and literature available in the area of epilepsy and quality of life. The first section of the chapter provides an overview of epilepsy including aspects such as treatment, genetic links and sudden unexplained death in epilepsy. The second section provides an overview of quality of life assessment. The third section describes quality of life mediated by age and gender. The next three main sections provide an overview on the physical, social and psychological impacts for people with epilepsy specifically relating to quality of life. The final section provides details on universal quality of life impacts for people with epilepsy. However, it should be noted that there is very little research completed in Ireland with regard to epilepsy. Therefore, much of the research and studies within this chapter are based in Europe and the U.S.

Chapter three provides detailed information on the research methods used in order to explore quality of life issues for people with epilepsy living in the Western region of Ireland. The aim of this chapter was to justify and explain the methodology used to carry out this research which was achieved through triangulation; the use of both quantitative and qualitative methods in the collection and analysis of data. The next section of this chapter describes the theoretical framework and guiding hypotheses of the research, followed by a description of the research strategy. The following section explains quantitative and qualitative research. The ensuing section describes the research design incorporating details on the focus group, questionnaire and interviews. The following section outlines the research process incorporating details on the sample of participants, response rate, pilot questionnaire and data analysis. The following section describes the ethical considerations of the research. Finally, the last section describes the strengths and limitations of the research.

The ensuing four chapters provide details of the findings and discussion of this research. The findings from the focus group, questionnaires and the interviews are integrated into each of the four chapters.

Chapter four is divided into three sections. The first section provides details in relation to the general background of respondents. The second section provides details of quality of life and physical impacts for people with epilepsy living in the Western region of Ireland. Finally, the third section endeavours to discuss the findings of the research and how these relate to previous research carried out in the area. This section will also explore the guiding hypotheses of the research.

Chapter five is divided into two sections. The first section provides details of quality of life and social impacts for people with epilepsy living in the Western region of Ireland. The second section provides a discussion of the findings of this research and how they relate back to previous literature in the area. The guiding hypotheses of this research will also be explored in this section.

Chapter six is divided into two sections. The first section provides details of quality of life and psychological impacts for people with epilepsy living in the Western region of Ireland. It also provides details on quality of life in relation to respondents overall well-being and respondent's subjective understandings of quality of life. The second section endeavours to discuss the findings of this research and how these relate to previous research carried out in the area. This section will also explore the guiding hypotheses of the research.

Chapter seven is divided into two sections. The first section provides details on universal quality of life impacts for people with epilepsy. These impacts are common threads which overlap with physical, social and psychological implications of epilepsy but may also have implications for social and health policy. The second section endeavours to discuss the findings of this research and how these relate back to previous research completed in the area.

Chapter eight outlines the main conclusions and recommendations drawn from the findings of this study. It highlights issues that people with epilepsy feel need to be taken into account when assessing quality of life. This chapter is divided into four sections. The first section concludes and makes specific recommendations relating to quality of life and physical impacts for people with epilepsy. The second section concludes and makes specific recommendations relating to quality of life and social impacts for people with epilepsy. The third section concludes and makes specific recommendations relating to quality of life and psychological impacts for people with epilepsy. Finally, the fourth section concludes and makes specific recommendations relating to universal quality of life impacts for people with epilepsy.

2.0 Literature review

2.1 Introduction

Historically, medicine was concerned with the management of serious disease and concentrated on areas such as the cure of disease and mortality. However, quality of life assessment has led to a change in focus and instead highlights areas such as morbidity and the effectiveness of medicine in controlling disease (Jacoby, 2000). The World Health Organization (WHO) published its definition of health in the 1940s which subsequently led to much clinical interest in quality of life issues. Over the next three decades the concept that non-medical measures could be significant indicators of medical outcome increasingly gained credibility, with the term quality of life (QOL) making its first appearance in the mid-1970s. The first use of the term QOL in epilepsy was documented in 1990 (Jacoby, 2000). The WHOQOL Group (1995:1405) defines quality of life as

> ...an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. It is a broad ranging concept, incorporating in a complex way individual's physical health, psychological state, level of independence, social relationships, personal beliefs and their relationship to salient features of the environment. This definition highlights the view that quality of life is subjective, includes both positive and negative facets of life and is multi-dimensional.

Quality of life is based on an individual's perceptions, beliefs, feelings and expectations (Camilleri-Brennan & Steele, 1999). In many ways it can be considered to be a subjective phenomenon. Further, O Boyle (1997:1875) states

> Quality of life is the difference, at a particular period in time, between the hopes and expectations of the individual and their present experience. It depends on the individuals past experience, present lifestyle and personal hopes and ambitions for the future. The gap between hopes and realities may be narrowed by improving the patient's functions (reality) through treatment or by reducing expectations through informed understanding of the limitations of their disease and acceptance of the risks involved in treatment in relation to expected benefits.

Quality of life assessment is an approach which unambiguously establishes the patient at the centre of attention. It is especially relevant to the elderly and people with illnesses where the preservation of quality of life rather than cure may be the main goal of treatment (O'Boyle, 1997).

This highlights the fact that for people with epilepsy medical care alone is not enough. In order to provide effective service provision emotional, psychological and social care also need to be provided for. Betts (2000:168) states

> Treating seizures is important (may be life saving); treating the whole patient is even more important. If we are to save the patients life with medication or surgery, it is important to consider the quality of that saved life.

According to Rapley (2003), sub-areas of quality of life research have developed specific definitions of quality of life. One example is in the area of medicine where many definitions of 'health-related' quality of life have been developed. Walker (1992:265) describes quality of life as

> ...a broad range of physical and psychological characteristics and limitations...health related quality of life is probably the key term and this is defined as the level of well-being and satisfaction associated with an individuals life and how this is affected by disease, accidents and treatment.

To date there have been numerous studies and research completed on the clinical aspect/treatment of epilepsy. Only in recent years have quality of life issues in epilepsy been explored and researched. According to Camilleri-Brennan & Steele (1999) the three main domains within quality of life are physical, social and psychological. Physical impacts refer to the person's ability in relation to daily activities. Social impacts refer to the ability to integrate and relate to family and other members of the community. Psychological impacts refer to aspects of emotional well being (Camilleri-Brennan & Steele, 1999). Within this research quality of life and physical impacts for people with epilepsy incorporate issues such as medication, seizure frequency, alcohol, sleep and seizure frequency, physical fitness and accidents. Quality of life and social impacts for people with epilepsy incorporate issues such as education, employment, driving restrictions, stigma and epilepsy myths. Quality of life and psychological impacts for people with epilepsy incorporate issues such as exercise and emotional well-being, understanding and adjustment to the diagnosis of epilepsy, depression & mood disorders, memory and concentration difficulties, and pseudo-epilepsy. Thompson et al (1993) cited in Bishop et al (2003:226/7) states

> The impact of epilepsy on a person's life is multidimensional and can span a range of functional and psychosocial domains. Along with the potential physical and cognitive problems associated with seizures, epilepsy has been associated with psychological and emotional problems, social isolation, and problems concerning education, employment, family life, and leisure activities.

This emphasises that medical treatment of epilepsy alone may not be sufficient; all aspects of an individual's life must be taken into account. As stated in Epilepsy Atlas (2005:3)

> Epilepsy leads to multiple interacting medical, psychological, economic and social repercussions, all of which need to be considered in order to understand fully the impact of this condition.

In brief, there has been increasing interest in the role of non-medical factors in treating patients. One area that is focused on is quality of life. The three main areas – physical, social and psychological are considered to be the main areas within quality of life research. Universal quality of life impacts for people with epilepsy are also explored within this research. These impacts are common threads which overlap with physical, social and psychological impacts for people with epilepsy but may also have implications for social and health policy. The next section of this chapter discusses issues relating to epilepsy such as treatment, genetic links and sudden unexplained death in epilepsy.

2.2 What is epilepsy?

According to Brainwave, the Irish Epilepsy Association, epilepsy is characterised by a tendency to have recurrent seizures. It is the most common but treatable neurological condition. It is said that one in 20 people will have a single seizure at some time in their lives. Generally, epilepsy is only diagnosed when a person has had more than one seizure. Anyone can develop epilepsy at any time. Our brains are made up of millions of nerve cells (neurons). A seizure occurs when the normal workings of the nerve cells are suddenly and temporarily interrupted. Some of the known causes of epilepsy include; head injury, stroke, drugs/alcohol, brain haemorrhage and meningitis. Epilepsy as a result of any of these causes is called 'symptomatic' epilepsy as an underlying cause has been found. When a cause cannot be found this is known as 'idiopathic' epilepsy. Once a diagnosis of epilepsy is made the patient is usually referred to a consultant neurologist.

A person with epilepsy can experience more than one type of seizure, but the pattern of seizures generally tends to remain fairly constant. Baker (2001:66) states

> Epilepsy is a chronic condition characterised by clinical uncertainty. A person with epilepsy faces uncertainty over the diagnosis of his or her condition, over whether and when seizures will occur, over the nature of the seizures and how best they can be controlled, and over whether they will, ultimately, remit.

Although epilepsy is usually classified by seizure type, it can also be classified by syndromes. The International League against Epilepsy (ILAE) has published a list of which are encouraged (see Appendix A). According to Pfafflin (2001) people diagnosed with epilepsy who become seizure free in the early stages they do not need additional support from medical treatment. Nevertheless, some studies suggest that approximately twenty percent of people with epilepsy who gain seizure control still experience negative consequences of their epilepsy. Further, Betts (2000:163) state

> Faced, for instance, with an increase in a patients seizure frequency, we tend to reach for our prescription pad rather than looking to see whether stress, social upset or a change in lifestyle has been responsible. This is partly because unless the physician has had psychiatric training, the importance of a social and psychological history is often under-estimated; and partly because our patients assume that we only want to hear about medical facts or symptoms and so may somatise their emotional difficulties.

Seizures can generally be controlled by drug treatment. However, for some people with epilepsy certain things can trigger their seizures examples of which include; lack of sleep, stress, non-compliance with medication, lights, noise and so on. Treatment of epilepsy will be discussed in the next sub-section.

2.2.1 Treatment

There are a number of different anti-epileptic drugs and these are prescribed for different types of epilepsy. For some people with epilepsy seizures can diminish over time (usually two years, seizure free) and medication can be withdrawn, under medical supervision (www.epilepsy.ie). Anti-epileptic drugs are free. However, epilepsy can often be misdiagnosed. According to Marshall & Crawford (2006) some conditions which may be misdiagnosed as epilepsy can include fainting, narcolepsy (suddenly falling asleep), non-epileptic attack disorder (NEAD) or psychological attacks (causes seizures but does not involve changes in electrical brain activity), drop attacks (no reason known why these can occur, consciousness is not lost and there is no treatment), low blood sugars, alcohol abuse.

Non-epileptic attack disorder (NEAD) is also referred to as pseudo-epilepsy and will be further discussed in the last section of this chapter when examining psychological impacts associated with epilepsy.

According to Marshall & Crawford (2006) a person's medical history and an eyewitness account of seizures is an integral part of the diagnosis of epilepsy. It is extremely important that there is an accurate account of the seizure. This gives the doctor a clear picture of what happened just before the seizure, to allow him/her to determine what time of day or night it took place, was there unusual sensations or symptoms of feeling unwell before the seizure, did the person stay conscious or were they unconscious and how did they feel when the seizure was over. Medical history from birth is important as it could reveal many factors such as heart problems or a history of febrile convulsions. Tests may also be carried out. The two main tests are an EEG (measurement of brain wave pattern) and MRI scan (detailed picture of the brain structure).

2.2.2 Genetic links

Although anyone can develop epilepsy, it should be noted that there is a link between certain syndromes and epilepsy. For example, children and adults with autism have a higher chance of developing epilepsy which may be as high as 30% (www.epilepsy.ie). For most people with autism and epilepsy a cause cannot be identified for either condition. As puberty is the most likely time to develop epilepsy for people with autism, hormonal changes during this time may be a reason for this.

According to Marshall et al (2006) about 25% of people with a learning disability also have epilepsy. This figure is higher with those who have a severe learning disability. Epilepsy is generally harder to control when there is an underlying brain condition such as cerebral palsy. Further, recent research suggests there may be a genetic link with some epilepsy. For instance, juvenile myoclonic epilepsy (JME) is idiopathic epilepsy but is also hereditary although the exact mode of inheritance is unclear. Some studies have found a link to specific genes. For instance, JME is linked to a gene which has been located on chromosome six. The difficulty remains however, that not all people who have this inherited gene will go on to have a seizure. It is most common in childhood and early adolescence.

Renganathan et al (2003) suggests juvenile myoclonic epilepsy may account for about 10% of all epilepsies. However, it is often an under-diagnosed syndrome so the figures may actually be higher. Epilepsy is usually not inherited although the predisposition to epilepsy can be passed on. However, is also depends on the history of epilepsy in the family as to whether or not epilepsy may be genetic in origin. Discussion with a GP is of vital importance and further discussion with a genetic counsellor may be appropriate in some cases. Sudden unexplained death in epilepsy (SUDEP) will be explained in the next sub-section.

2.2.3 Sudden unexplained death in epilepsy

SUDEP is sudden, unexpected, witnessed or unwitnessed death in people with epilepsy. The mechanism of SUDEP is uncertain although essentially it may be respiratory or cardiac. Completed research has suggested that there can be risk factors in relation to people with epilepsy and SUDEP. Precipitating factors include; poor seizure control, nocturnal seizures or unwitnessed seizures, abrupt and frequent changes in medication or non-compliance with medication, alcohol, drugs, tiredness and stress (www.sudep.org).

Epilepsy does have increased mortality rate especially in young people and people with severe epilepsy. Epilepsy related deaths have not always been accurately recorded or recognised (Marshall & Crawford, 2000). The awareness and accurate recording of epilepsy in a patient, alongside medical history and the exact account of the circumstances of death, is essential to providing us with the number of epilepsy related deaths occurring in this country. Nashef & Sander (1996:235) state

> In people with uncontrolled chronic epilepsy there is an excess mortality directly attributable to the epilepsy itself. This is largely due to accidental and non-accidental deaths occurring during or immediately after seizures. Most sudden unexpected deaths in epilepsy fall within the latter category. To acknowledge rather then conceal these deaths is essential before prevention strategies can be addressed.

A recent study in the U.K. (Gaitatzis et al, 2004) compared the life expectancy of people with newly diagnosed epilepsy with that of the population of the same age and gender. Gaitatzis et al (2004:2427) assert that

> Epilepsy is a potentially life-threatening condition and carries a risk of premature mortality. This has been consistently shown both in population-based studies and in studies of more selected populations.

In the study 564 patients with epilepsy were followed for 15 years; 177 deaths were recorded. The authors found that people with idiopathic epilepsy can have reduced life expectancy of up to 2 years and those with symptomatic epilepsy have reduced life expectancy of up to ten years with reference to the general population. The authors found the reduction in life expectancy was highest at the time of diagnosis of epilepsy and that this risk diminishes with time. Further, they found that neither seizure frequency nor antiepileptic drug treatment influenced the mortality rate.

A study completed by Salmo & Connolly (2002) reviewed mortality rates in the west of Ireland over a ten-year period. The authors reviewed 3,103 autopsy reports and found 22 cases deemed to be sudden unexplained death in epilepsy (SUDEP) with all cases having a history of idiopathic epilepsy. Forty-five per cent had been found dead in bed. The average age was 38 years and 68% were males. According to this study the prevalence of epilepsy in the region was 0.46% and therefore the incidence of SUDEP 1:394 over the ten year period studied. Sixteen cases had anti-epileptic medication levels and out of these cases 68% had absent or low levels at post-mortem. This may suggest that non-compliance in taking medication may play a role in SUDEP. The authors of this study concluded from their research that compliance with treatment and numerous nightly observations for people with epilepsy most at risk of sudden death in epilepsy could help reduce its incidence (Salmo & Connolly, 2002). Another study completed in Ireland by Langan et al (1998) examined the incidence of sudden unexplained deaths in epilepsy in South Dublin and Wicklow. This study was completed retrospectively from May 1992 to 1994, and prospectively from May 1994 to 1995. Langan et al (1998:357) states

> In our population-based study we have found an incidence of SUDEP of 1:680/year and this is consistent with the findings of other studies. There are approximately 18,000 individuals with epilepsy in the Republic of Ireland, and using the incidence rate which we have calculated, an estimated 25 may die unexpectedly each year. The next step must be to concentrate on the characteristics of these patients with a view to identifying the factors that make them vulnerable.

The next section of this chapter endeavours to provide an overview of quality of life assessment in epilepsy.

2.3 Quality of life assessment

Quality of life research in epilepsy is of paramount importance given the chronic and unpredictable nature of epilepsy and the potential effects it may have on quality of life. Steinbuchel et al (2000) suggest

> To develop a comprehensive instrument for the assessment of all aspects of epilepsy, it is necessary both to define quality of life in epilepsy as comprehensively as possible, and to empirically determine the areas of importance.

Hopkins (1992:3) proposes the uses of quality of life assessments

> First a measure could provide baseline against which the effectiveness of subsequent interventions could be measured. Secondly, it may well draw attention to some area of impairment that a busy or inexperienced clinician may have overlooked...thirdly, it could be argued that a measure of health status applied at the onset of a patient episode could determine the severity of impairment, and therefore the priority that the clinician has to give that particular patient in allocating resources within his or her clinical practice.

According to Rapley (2003) medicine has adopted three general approaches to quality of life assessment. Firstly, studies which report physician or patient judgements of the patient's quality of life consisting of symptoms and functional status. Secondly, patient evaluations of their health status which consist of their values and preferences. Lastly, personal quality of life research (PQL) which evaluates individuals' own judgements about quality of life consisting of the effects of their condition and treatment. Jacoby (2000:48) suggests

> Because quality of life is a highly individual construct, it can only be measured by taking into account patients' own values and preferences.

Baker (2000) suggests almost all recent available quality of life assessments have been developed in the U.K and the U.S.A therefore, requiring cross-cultural validation. The next section of this chapter provides details on quality of life implications of epilepsy as mediated by age and gender. It also provides an overview of a reliable and valid inventory developed to evaluate health related quality of life in adolescents with epilepsy, namely the QOLIE-AD-48.

2.4 Quality of life as mediated by age and gender

Incidence of epilepsy is slightly higher in males (Christensen et al, 2005; Marshall & Crawford, 2006). Christensen et al (2005) completed a study in Denmark. The aim was to look at gender differences in unselected populations of people with epilepsy. Overall the authors found no gender difference.

However, they do suggest that there is a gender susceptibility to the development of certain types of epilepsy. According to Sander (2005:1/2)

> In most studies, the overall incidence of epilepsy…in developed societies has been found to be around 50 cases per 100,000 persons per year…it has been noted that around half of people developing epilepsy do so before the age of 15 years. Recent epidemiological evidence suggests, however, that increasing numbers of patients are developing epilepsy in old age…most, but not all, studies have found a slight male preponderance.

The marital status of people with epilepsy was examined by Wada et al (2004). Wada et al (2004:35) states

> In the present study, epilepsy was the cause of divorce in 7 of the 29 patients…of these patients, only one patient had informed the spouse of the disease before marriage…a close relationship existed between the presence or absence of marriage and the presence or absence of a job among male patients…we concluded that epilepsy has negative effects on the patient's married life.

Callaghan et al (1992) found that the majority of people with epilepsy in their study were single. Callaghan et al (1992:18) suggest

> Social and environmental factors may also contribute to low martial rates since patients with epilepsy and especially patients with poor seizure control, lead restricted social lives and may have a less opportunity in meeting a suitable partner.

Another issue highlighted with regard to age was age of onset of epilepsy. Jacoby et al (1996) completed a study on the clinical course of epilepsy and found that age at epilepsy onset was a significant predictor for depression, stigma and marital status. Within this study people with frequent seizures were more likely to experience anxiety and depression than those who were seizure free.

2.4.1 Childhood and adolescent epilepsy

According to Sillanpaa et al (2004:976)

> Childhood onset epilepsy has a long-term adverse impact into adulthood. The major impact is in the groups that remain on medications regardless of whether or not they are in remission. Encouragingly, it appears that those in remission off medications, although having a higher rate of educational problems and lower marriage and fertility rates than population-based controls, perform similar to the general population in terms of employment, holding a driver's license and SES (socioeconomic status).

A study completed by Jalava et al (1997) assessed the effect childhood-onset epilepsy has on adult social adjustment and competence in Finland. The participants consisted of 245 children under the age of 16. Cross-sectional studies were completed every 5 years. Participants were contacted again and data gathered after a 35 year follow-up period. Random controls of the general population were selected for each participant with epilepsy. The authors found that overall education levels and socioeconomic status were significantly reduced in participants with epilepsy compared with controls. The unemployment rate for participants with epilepsy was 3 times higher than controls and for those who were in employment 77% of them had not disclosed their epilepsy to their employer or colleagues. Overall the study concluded that many of the participants with childhood-onset epilepsy had poor social adjustment and competence in adulthood.

Puberty is a common time in which epilepsy can start. Teenage years are a time where friendships, school and socialising are important. Many changes occur and having epilepsy can be an added challenge at this sensitive time. It is important to note that having epilepsy during adolescence may have different implications than having it as a child or an adult. According to Cramer et al (1999) issues that are important to note include the broad range of maturity within this age group (11-17 years), differences in independence, experience and responsibility and possible volatility of emotions. This study developed a reliable and valid inventory to evaluate health related quality of life in adolescents with epilepsy (The QOLIE-AD-48). This inventory has eight subscales; epilepsy impact, memory/concentration, attitudes towards epilepsy, physical functioning, stigma, social support, school behaviour, health perceptions and a total summary score. Another study completed by Devinsky et al (1999) used the aforementioned inventory (QOLIE-AD-48) to examine possible risk factors for poor health-related quality of life (HRQOL) in adolescents with epilepsy. Participants consisted of 197 adolescents, age 11-17 years (101 girls/96 boys) in the US and Canada. Older participants (14-17yrs) with more severe epilepsy, more symptoms of neurotoxicity and lower socioeconomic status reported poorer overall HRQOL. This was the case regardless of duration of epilepsy. Older participants also seemed to be more affected by perceived consequences of epilepsy. However, the younger participants (11-13yrs) reported poorer HRQOL within the social support subscale.

Also within this subscale female participants reported better HRQOL than male participants. Devinsky et al (1999-1719) states

> At present, older adolescents, those with more severe epilepsy and with symptoms of neurotoxicity have been identified as being at risk for experiencing poor HRQOL. Girls may also be at higher risk than boys. If specific strategies to prevent or improve HRQOL issues for these vulnerable patients can be developed, health care delivery to adolescents with epilepsy may be enhanced.

A study completed by Austin et al (1996) compared quality of life in adolescents with active or inactive epilepsy and asthma in the US. Participants consisted of 117 adolescents with epilepsy and 111 with asthma. The study explored 19 different dimensions in three quality of life domains, namely psychological, social and school. Austin et al (1996:1229/1235)

> Persons with asthma constitute a good comparison group because both asthma and epilepsy are episodic conditions that require daily medication during active treatment. We had anticipated that the QOL of epilepsy sample as a whole would be similar to that of the asthma sample because substantially more of the epilepsy subjects had inactive conditions as compared with asthma subjects.

However, the authors found adolescents with epilepsy to have poorer overall quality of life, than that of the asthma sample. Moreover, the study found there were differences within the epilepsy and asthma sample in 13 of the 19 areas, with the most differences being apparent in the school domain. This study found that severe seizures in girls were associated with more problems and therefore, highlights the need for sex-severity interactions to be explored in future research. There were three main explanations given within this study as to possible reasons adolescents with epilepsy had poorer quality of life than those with asthma. The first was a greater difficulty adjusting to the diagnosis of epilepsy as there is greater stigma attached to the condition. Second, the nature of the condition; witnessing a seizure can be more dramatic and attention getting than an asthma attack. Also people with asthma generally have more control over the attack than in epilepsy. Finally, epilepsy and/or anti-epileptic medication interfere more with cognitive functioning and therefore affects aspects such as adjusting to the diagnosis and educational achievement.

The next three main sections of this chapter provide an overview on the physical, social and psychological impacts for people with epilepsy specifically relating to quality of life. The next section of this chapter discusses quality of life and physical impacts for people with epilepsy incorporating anti-epileptic medication, seizure frequency, alcohol, sleep and seizure frequency, physical fitness and accidents.

2.5 Quality of life and physical impacts for people with epilepsy

Quality of life and physical impacts for people with epilepsy refer to the person's ability with regard to daily activities (Camilleri-Brennan & Steele, 1999). These impacts include medication, seizure frequency, sleep and alcohol, physical fitness and accidents.

2.5.1 Anti-epileptic medication

Approximately 70% of people with epilepsy can be seizure free with the correct treatment (EUCARE, 2001) i.e. anti-epileptic drugs (AEDs). Nonetheless, these drugs can pose many side effects for the person taking them including drowsiness, weight gain, nausea, double vision and skin rashes.

In recent years the issue of 'generic' copies of anti-epileptic drugs being prescribed for people with epilepsy has come to light in countries such as the U.K and Canada. The move towards these generic drugs has been controversial. A generic drug means that it is a chemically equivalent copy of a brand name anti-epileptic drug for which the patent has expired. A generic drug is typically less expensive and sold under a common or 'generic' name for that drug (Brainwave, 2006). The main issue with these generic drugs being used for people with epilepsy is that subtle differences in them can have profound effects. Epilepsy Action (Europe's largest member led epilepsy organisation) based in the U.K. completed a survey in 2003. The survey was designed to explore experiences of people with epilepsy in relation to their use of anti-epileptic medication. The questionnaire was completed by 1,851 people with epilepsy and found that 23% of people had more seizures and 32% had more or different side-effects when switched to generic drugs. It is important to appreciate that even one seizure can have an enormous impact on a person's quality of life; for example, it would mean the immediate loss of a driving licence for 1 year in Ireland.

A study by Crawford et al (1996:1) suggests

> That money saved by generic prescribing is outweighed by negative health gain for the person with epilepsy, increased work in general practice, and increased social costs.

A study by Crawford et al (2006) reviewed potential problems in using generic anti-epileptic drugs. In relation to epilepsy, the avoidance of seizures and keeping adverse effects to a minimum are the main aim. For people with epilepsy who are in remission even a single seizure can have an enormous effect. Socially it could mean the loss of employment or personally it could mean the possibility of injury and/or loss of self-esteem. Therefore, it can be said that the use of generic substitutes in treating people with epilepsy has more implications than for treating other health conditions (Crawford et al, 2006).

The above concerns have led to restrictions being put in place in relation to the use of generic anti-epileptic drugs in some countries. For example, according to Crawford et al (2006) in the U.K. generic anti-epileptic drugs can only be dispensed when the prescription is written generically. Healthcare systems are under greater pressure due to increasing numbers of older people and greater expectations from patients. However, the introduction of generic anti-epileptic drugs could have a costly affect on the health and quality of life of people with epilepsy. Seizure frequency will be discussed in the next sub-section.

2.5.2 Seizure frequency

Marshall & Crawford (2006:5) state

> Seizure threshold...is the brain's individual level of sensitivity to seizures, and is a major factor in the development of epilepsy.

Baker & Jacoby eds. (2000:295)

> The level of attention now given to the topic suggests that there is widespread acceptance in the epilepsy research and clinical communities that data on seizure frequency alone are insufficient to provide a full picture of the position for people with epilepsy.

A study by van Hout et al (1997) investigated, retrospectively, the relationship between seizure frequency and both health costs and quality of life. This was conducted through thirty neurologists in France, Germany and the U.K whereby each neurologist enrolled ten patients with epilepsy.

Participants consisted of 101 from France, 102 from Germany and 97 from the U.K with 45% being female. Cockerell et al (1994) cited by van Hout et al (1997) estimated that the cost of epilepsy annually in the U.K was £1,930 million, with over 69% of this due to indirect costs such as unemployment. The study by van Hout et al (1997) confirms that epilepsy inflicts serious socioeconomic costs. Van Hout et al (1997:1225)

> In addition, the hypothesis that there is a positive relationship between seizure frequency and costs and a negative relationship between seizure frequency and quality of life is confirmed. However...the results do not imply that decreasing the number of seizures per patient would also decrease costs and improve quality of life.

A study by Fisher et al (2000) assessed the characteristics of seizures and determined the limitations 1,023 people with epilepsy encounter because of their seizures in the U.S. This study found that respondents' understanding of the classification of their seizures was limited. It also found that a significant number of respondents continue to experience seizures and side effects of anti-epileptic medication. Within this study respondents had lower marriage rates, struggle with education, higher rates of unemployment and poor self-image. The unpredictability of epilepsy is a key factor in how people perceive their quality of life. Fisher et al (2000:39) states

> Respondents listed uncertainty and fear of having a seizure as the worst thing about having epilepsy.

Seizures may occur at any time, for some people this may happen with little or no warning. Harden et al (2007) evaluated the effect of seizure severity on quality of life in epilepsy. The participants consisted of 118 women between 18-45 years of age. The authors found an association between seizure severity and quality of life with the results suggesting may increase the development of worry and anxiety and/or socially avoidant behaviours. Moreover, the physical facets of seizure severity can impact on the day-to-day activities of people with epilepsy (Harden et al, 2007). Other issues that can affect seizure frequency and quality of life are lack of sleep and alcohol. These two issues will be discussed further in the next sub-section.

2.5.3 Alcohol, sleep and seizure frequency

In the case of alcohol consumption people with epilepsy may need to take more care than that of the general population.

According to Brainwave there are a number of reasons for this some of which include; alcohol can interfere with anti-epileptic medication.

Alcohol can inhibit levels by preventing medication reaching the bloodstream and in turn the person does not have the levels required to control seizures. A seizure can be triggered in a person with epilepsy by large amounts of liquid such as alcohol and water. Heavy drinking can increase the risk of seizure due to the combination of late nights, lack of sleep, forgotten tablets. Moreover, Brainwave (www.epilepsy.ie) states

> Excessive drinking over a long period may result in temporary or permanent brain damage, which in turn can increase the risk of many conditions, including epilepsy. One in five alcoholic men and one in ten alcoholic women over the age of 25 years experience epileptic seizures. In most cases the seizures result from the withdrawal of alcohol after an intense bout of drinking...in some cases of alcoholism, established epilepsy develops as a result of brain damage caused either by the direct effects of alcohol on the brain, or head injuries sustained while drunk.

Seizures are more frequent during sleep (Langan et al, 1998). A Dutch study completed by deWeerd et al (2004) sought to determine the prevalence and characteristics of subjective sleep disturbance in people with epilepsy and the impact this might have on quality of life. Participants consisted of 486 patients and 492 controls. The study found that the respondents' sleep disturbance was twice as prevalent in patients with epilepsy and quality of life was significantly and independently impaired in those with epilepsy. Further, epilepsy was significantly associated with excessive daytime sleepiness. According to deWeerd (2004:1403)

> Thus we propose that sleep disturbance in patients with partial epilepsy, whatever the etiology, has a significant negative association with quality of life beyond that attributable to epilepsy and its treatment alone.

Further, Malow (2007:37) states

> Sleep and epilepsy are interrelated, with sleep state influencing seizures and IEDs. Conversely, epilepsy and its treatment affect sleep. Sleep disorders may coexist with epilepsy, and treatment of these disorders may assist in the management of the seizure disorder. Deciphering the relationship of seizures to sleep may lead to improved knowledge of how seizures are initiated and to more effective treatments for epilepsy.

Physical fitness and epilepsy will be discussed in the next sub-section.

2.5.4 Physical fitness

Steinhoff et al (1996) assessed leisure time and physical activity in patients with epilepsy and compared them to a control sample from the general population. There was no difference between the two groups in relation to leisure time activities at home which were mostly passive activities (reading, computer games and watching television). However, there were differences between the two groups in relation to leisure activities outside the home (visiting the cinema, attending concerts) patients with epilepsy being significantly less active than the control sample. This study found that one main reason for the inactivity of people with epilepsy was the lack of information from health professionals with less than half of participants reporting being sufficiently informed. Steinhoff et al (1996:1221) state

> We conclude that patients with epilepsy suffer from a considerable lack of physical fitness that might have an important impact on their general health and quality of life. In addition to overprotection and reduced mobility, the questionnaire revealed insufficient knowledge among health professionals and sport instructors as a major factor contributing to these results.

A study by Wong & Wirrell (2006) also compared physical activity in children and teens with epilepsy with a control sample and found that those with epilepsy were less active than controls in both total sports and group sports activities. Nakken (2001:143) suggests

> People with epilepsy comprise an extremely heterogeneous group of patients. Different patients may react differently to physical exercise. Counselling on this topic must therefore be individualised as each patient presents individual challenges. The recommendations should be tailored to meet the needs of the patient, keeping in mind the risk-benefit ratio; calculated risk of injuries should be balanced against the risk of physical, psychological and social problems resulting from isolation and inactivity.

In order to participate in sport or leisure activities appropriate, clear and concise information must be provided to the person with epilepsy. Accidents and epilepsy will be discussed in the next sub-section.

2.5.5 Accidents

Cornaggia et al (2006) completed a cohort study in relation to accidents at work among patients with epilepsy within eight European countries. Both patients with epilepsy and the control group were given diaries to record details of any accidents/illnesses at work, including severity, circumstances, causes, consequences and possible relation to seizure for those with epilepsy over a 1-3 year period.

In both groups injuries sustained at work were mild. In patients with epilepsy the risk of accidents was not affected by seizure type or frequency. However, this study found that patients with epilepsy are at a higher risk of accidents at work than that of the general population. Beghi et al (2002) also found that patients with epilepsy were at a higher risk than that of the general population. The authors completed a study which assessed the risk of accidents and illnesses in people with epilepsy and evaluated the proportion of those risks that were due to epilepsy. The study was based on 6 Western European and 3 Eastern European countries. Participants consisted of 951 people with epilepsy and 909 controls. Beghi et al (2002:1082) state

> Thirty percent of illnesses and 24% of accidents were seizure related. Recurrent seizures have been implicated as a risk factor for spontaneous medical events and injuries. This reflects the fact that everyday life risks in epilepsy may be partly caused by seizures, but that patients with epilepsy under satisfactory pharmacologic control are not at any significantly higher risk of illnesses and accidents than is the general population.

In addition a study completed by Sheth et al (2004) analysed multiple-cause of mortality data files for the years 1995-1997 to determine the number of seizure-related and non-seizure related crash fatalities in the U.S per year, as well as any associated medical conditions. The authors found that seizure-related driver fatalities are rare (0.2%). However, compared to drivers with other medical conditions, there is an increased risk of fatal crash for drivers with epilepsy. Sheth et al (2004:1006) concluded

> A more uniform and reliable system of mortality reporting and a greater emphasis on causal medical conditions in drivers (such as epilepsy) would assist in individualising the decision to grant or deny driving privileges to patients with epilepsy.

Further, Drazkowski et al, (2003) evaluated whether changing the seizure-free interval in Arizona from 12 months to 3 months affected the number of seizure-related motor crashes. This study was conducted for 3 years before (1991-1993) and 3 years after (1994-1996) the seizure free interval was lowered from 12 to 3 months. Within the 6 years of study, 614,000 crashes were recorded in Arizona. From these 859 crashes were linked to all medical conditions, of which 125 were seizure related during the period 91-93 and 136 were seizure related the period 94-96. Therefore, the authors of this study found that in the state of Arizona reducing the seizure-free interval from 12 to 3 months did not significantly increase the rate of seizure-related crashes.

In conclusion, it is apparent that there are many physical impacts which may affect quality of life for people with epilepsy. Firstly, people with epilepsy may experience side effects from their medication which impacts on their quality of life including drowsiness, weight gain and double vision. In addition, studies have suggested that research on seizure frequency alone is inadequate in providing a full description of the position of people with epilepsy. Moreover, other studies have confirmed that there is a negative relationship between seizure frequency and quality of life. Other issues which can affect seizure frequency include lack of sleep and alcohol consumption. These issues can negatively affect quality of life for people with epilepsy. Secondly, people with epilepsy suffer from lack of physical fitness which may impact on their general health and quality of life. Finally, studies have found that people with epilepsy are more likely to have accidents at work than the general population. The next section of this chapter endeavours to provide details on quality of life and social impacts for people with epilepsy.

2.6 Quality of life and social impacts for people with epilepsy

Quality of life and social impacts for people with epilepsy refer to their ability to integrate and relate to members of their family and their community (Camilleri-Brennan & Steele, 1999). These impacts can include education, employment, driving regulations, and stigma and epilepsy myths. According to Austin and deBoer (2000:110)

> Adults with epilepsy have been found to have a higher prevalence of social problems, including social isolation and problems with adaptation, than people in the general population.

Once a person has been diagnosed as having epilepsy i.e. they have had more than one seizure, the main focus is on achieving seizure control. The area of psychosocial support for the individual is generally secondary to this. Suurrmeijer et al (2001:1160) states

> ...health professionals should be aware of the significance of the psychosocial functioning of the patients and the role it plays in the achievement of a good quality of life.

Education and epilepsy will be explored in the next sub-section.

2.6.1 Education

Callaghan et al (1992) completed a study on epilepsy and employment, marital, education and social status. According to Callaghan et al (1992:18)

> This study reveals a high unemployment rate among epileptic patients when compared with the national average for employment during the period of the study. Certain factors emerged from the study which would have contributed to the high unemployment levels. For example, an association was found between high unemployment and poor seizure control. Other factors which also contributed to high unemployment levels were both social status and poor educational achievements…the overall educational achievement was poor with only 5% achieving third level education.

According to Brainwave, the Irish Epilepsy Association (1991) cited in Senior (2003:67)

> Ireland is the only country in the E.U that has no special educational or assessment facilities for children with more difficult forms of epilepsy.

A recent study completed by Senior (2003) examined the educational, medical and advisory provision for children with epilepsy in Ireland. This research involved the use of questionnaires posted to parents of children with epilepsy. A total of 139 parents were involved in this study. In one area parents were asked about their child's adjustment to their epilepsy and findings of which are displayed in the following table.

Table 1: Illustrates children's adjustment to condition

Reaction	N	%
Bothered by it	44	67.7
Regards it as a nuisance	29	44.6
Feels it is unfair	21	32.3
Has a positive attitude	17	26.2
Emotionally upset by it	13	20.0
Uses it as an excuse	9	13.8
Ashamed	9	13.8

Source: Senior (2003:121)

The above table summarises how the children felt about having epilepsy. Given that 67.7% were 'bothered by it', it would appear that a large number of children have difficulty adjusting to their epilepsy. Further, 29% of parents reported their children have suffered from undue anxiety and depression because of their epilepsy.

It is apparent that psychological supports need to be extended within schools so as to support children with epilepsy in cognitive, social and emotional needs as they progress through the educational system. Further, within this study parental reaction to the diagnosis of epilepsy was varied. They experienced emotions from anxiety (62%), fear (51%), and anger (23%) to rejection (5%). However, 85% of parents did not attend counselling to deal with the diagnosis of epilepsy which may be a significant factor.

It has been suggested that academic underachievement is common in people with epilepsy particularly amongst children and adolescents. This may be related to a number of factors including negative parental attitudes but also cognitive difficulties such as poor concentration and memory difficulties. Epilepsy Action conducted a workshop for young people with epilepsy and findings were reported by Blake & Coulson (2003). Participants consisted of 38 young people with epilepsy aged 15 to 25 years. The majority of participants were sent home or to hospital from school after seizures and 65% felt this had an impact on their educational achievements. Extra time during exams was given to 25% of respondents. However, many participants did not know that extra time may have been available to them. Another issue was bullying by peers at school. 40% of participants reported being bullied and felt that this was due to their epilepsy. Participants felt that school staff were ill equipped in first aid to deal with epilepsy and that attitudes varied, ranging between patronising to over sympathetic (Blake & Coulson, 2003).

Another issue within education involves the perceptions of teachers in relation to epilepsy. A study completed by Katzenstein et al, 2007 examined how the label epilepsy related to teachers' ratings of academic performance compared with the child's actual academic performance. The study took place in the U.S and consisted of 125 children. Katzenstein et al (2007:431) found

> Teachers may have a negative perception of the academic abilities of children with epilepsy. Their perception of the label epilepsy may influence how teachers rate the academic performance of children and how the children are treated in the classroom. These perceptions could have significant effects on the child psychosocially and academically.

Employment and epilepsy will be discussed in the next sub-section.

2.6.2 Employment

Aldenkamp & Hendriks (2000:34) state

> Being able to obtain and maintain a satisfactory job and income is obviously relevant to an individuals psychosocial functioning, if only because unemployment introduces economic pressure, and may reduce opportunities for social interaction and leisure activities. Unfortunately, unemployment and underemployment of people with epilepsy are much more frequent than in the general population.

Even though epilepsy is very common there are still many misconceptions attached to this condition. One of the areas in which people with epilepsy feel affects their quality of life is employment (Fisher et al, 2000, Jacoby et al, 2005). Jacoby et al (2005) completed a study of a random sample of 560 UK companies. Within this study a postal questionnaire was used to re-examine employer attitudes to people with epilepsy in the U.K. in light of recent legal, medical and social changes. The majority of employers had jobs within their companies for people with epilepsy. However, twenty one per cent of employers felt that employing someone with epilepsy would be an issue. Such issues for employers included fear of higher insurance premiums, health and safety concerns, and the effects on workers if they were to witness a seizure. This study suggests that misconceptions among employers have not changed that much, despite increasing awareness of this condition. Further, this study highlighted that the employment status and progression of people with epilepsy in the workplace may be influenced by employer and co-worker attitudes. Jacoby et al (2005:1984) states

> Epilepsy is a hidden disability, meaning that it is virtually impossible to know exactly how many people with epilepsy whose seizures are well controlled are successfully holding down jobs without ever having revealed their condition to employers or co-workers.

Moreover, Jacoby (1995) examined the current and recent employment history of 494 people with well controlled epilepsy in the U.K. The majority of participants were in employment at the time of the study and epilepsy did not seem to affect employment history. Participants who were not currently employed did not feel that it had anything to do with their epilepsy. However, a third of respondents felt that their epilepsy did affect their ability to obtain employment. In conclusion, the author suggests that generally people with well controlled epilepsy do not encounter problems with regard to employment.

A study completed by Harden et al (2004) assessed the reaction to epilepsy in the workplace in New York City. The authors developed three vignettes – epilepsy, depression and multiple sclerosis – with eight identical questions in each vignette and distributed them to employees in two different companies. This study found that respondents were more likely to experience anxiety at the thought of interacting with a colleague with epilepsy than with a colleague with depression or multiple sclerosis. This was also the case with regard to level of comfort providing first aid. Harden et al (2004:1139) state

> Our preliminary work suggests that epilepsy as a term and as an idea carries a risk of social avoidance in the workplace, even though a seizure has not been witnessed. Most important, this work suggests that increased education about first aid for seizures may help reduce the actual stigma of epilepsy in the workplace.

Moreover, Smeets et al (2007:354) recommend

> ...specific training interventions that focus on increasing the self-efficacy and coping skills of people with epilepsy so that these individuals will be able to accept their disorder and make personal and health-related choices that help them to achieve better employment positions in society.

With specific regard to Ireland, Carroll (1992) completed a follow-up study of all trainees who had completed social skills training programmes between the years 1986-1990. There were 101 people who completed the programmes. Of those 38 people with epilepsy took part in this study. The social skills training programmes were run by Brainwave, FAS and the State training and employment authority. Participants were interviewed about their current employment status. Three areas of concern were apparent in this study, namely, employment, training and counselling. The author found that 61% of participants were currently unemployed. There was great difficulty in finding the participants training programmes that were suitable. In the area of counselling Carroll (1992:130) state

> The feelings of depression and frustration expressed by some of those interviewed must also give rise to concern. Anger, resentment and loss of confidence were often present. These make personal relationships extremely difficult and can have the effect of accentuating further prejudices which people come across amongst the public and employers.

However, there were positive implications of completing the above mentioned programmes as 66% of participants felt that it had helped them increase their self-confidence and social skills.

Bautista & Wludyka (2007) completed a study in the U.S to determine variables associated with employment in patients from an epilepsy centre. There were 262 participants aged between 18 and 65 years. The majority of participants had achieved high school education but not gone on to further education and most did not drive. The authors identified three variables independently associated with employability; higher family income; belief that work is important for personal reasons; and decreased fear of discrimination at work. Further, Bautista & Wludyka (2007:92) state that

> Our findings indicate that nonclinical and psychosocial variables are significantly associated with employment in our epilepsy population. Interestingly, in our study the majority of clinical variables directly related to epilepsy, such as age at seizure onset, seizure duration, presence of convulsions, and severity of adverse reactions to AEDs, were not associated with employment.

A study by Collings & Chappell (1994) examined the inter-relationships between employment status, employment experiences, background, educational and epilepsy related variables. This study consisted of 1709 people with epilepsy who were members of the British Epilepsy Association (BEA) in England and Wales. The authors found that almost 60% of participants were employed, and 12% were unemployed. There were two significant findings within this study; that good medical care was linked to employability and being seizure free lessened the likelihood of being unemployed. Collings & Chappell (1994:260) state

> ...there is increasing interest in seizure severity as a measure of treatment outcome in epilepsy and this variable is now seen as a major factor contributing to the overall quality of life of people with epilepsy.

The next sub-section will discuss driving regulations for people with epilepsy.

2.6.3 Driving regulations

Another social issue affecting the quality of life of people with epilepsy is driving restrictions. These restrictions can adversely affect other areas such as job restrictions, feeling of dependency, school and other social restrictions (Fisher et al, 2000). According to Baker & Spitz, (1970) cited in Fisher et al (1994:676)

> About 1 in 10,000 accidents was attributed to epilepsy, a small percentage as compared with that of accidents attributed to alcohol or to sudden (presumably cardiac) death at the wheel....approximately 6 in 10,000 traffic deaths are believed to be caused by natural death at the wheel.

In Ireland driving regulations (1999) for people with epilepsy stated that they had to be seizure free for one year preceding the date of medical examination, may be certified to drive for a limited period of time but cannot drive lorries, buses or heavy goods vehicles. Amendments were made to driving regulations in 2004. These were significant changes in that they allow a person with epilepsy to drive who have had sleep seizures only, for two consecutive years where a Consultant Neurologists certification is provided. The one-year rule can be reduced to six months in certain circumstances where a person with epilepsy has had a provoked seizure, along with a Consultant Neurologists certification. A person with epilepsy who experiences simple partial seizures only, can drive (as consciousness is not lost) along with a Consultant Neurologists certification (Brainwave, 2004). If a person has a licence before developing epilepsy or if they have not had a seizure in more than a year, have regained a licence and unexpectedly have a seizure it is imperative that they stop driving immediately. In a study completed by Fisher et al (2000), twelve per cent of respondents to a questionnaire admitted to having a car accident as a direct result of experiencing a seizure. Fisher et al (2000:41) suggest that

> Limitations on lifestyle was second to fear as a category of important subjective disability in epilepsy. The largest single lifestyle limit was being unable to drive, listed as 10.9% of our survey population as the 'worst thing' about having epilepsy. Not being able to drive interacts with feelings of dependency and limits on job, school and social activities.

Although the restrictions for driving in Ireland seem reasonable and are in the best interest of all citizens, it is important to note in each instance of the new regulations a person requires a Consultant Neurologists certification. There is a huge lack of resources in all areas of neurology services and lengthy waiting times for appointments in Ireland. Therefore it may take a person with epilepsy some time to receive this certification. This can impact greatly on their quality of life. Stigma and epilepsy myths will be explored in the next sub-section.

2.6.4 Stigma and epilepsy myths

Stigma is still an issue for people with epilepsy despite worldwide attempts by epilepsy associations to increase awareness and accurate information in relation to epilepsy. Goffman (1968:13) defines stigma as

> An attribute that is deeply discrediting.

Interpreting Goffman's work, Susman (1994:16) states

> Goffman brings to light the overriding theme of subsequent social science research, i.e. that it is not the functional limitations of impairment which constitute the greatest problems faced by disabled individuals, but rather societal and social responses to it.

Scambler & Hopkins (1986) explored the perceptions of epilepsy and its impact personally and socially on a sample of 94 people with epilepsy aged 16 years and over living in and around London. The authors made a distinction between enacted and felt stigma. An instance of discrimination against a person with epilepsy is enacted stigma. This excludes fair or legitimate discrimination such as driving restrictions. Felt stigma is multifaceted. It is the fear of enacted stigma, but also includes a feeling of shame associated with being epileptic. The authors found that felt stigma was more prevalent than enacted stigma. Many of the respondents within this study were tremendously upset by the diagnosis of epilepsy. According to Scambler & Hopkins (1986:31)

> ...they felt they had been ascribed a status or identity which would, or could, distance them from normal people....Most saw members of the public as misinformed, hostile and predisposed to unfair discrimination.

For the respondents of this study 'disclosure' was an issue, 72% of the respondents were in full time employment but had not disclosed their epilepsy to their employer and because of this they were living with the day-to-day possibility of 'exposure'. This method of concealment was also evident in a study completed by Schneider & Conrad (1980). Further, a study completed by Westbrook et al (1992) of adolescents with epilepsy found that more than half kept their epilepsy a secret, while 70% of adolescents never or seldom talked about their epilepsy. Jacoby (1994) revised Scambler & Hopkins distinction between felt and enacted stigma in a study of people with epilepsy in remission. The results of the study supported Scambler & Hopkins original distinction. Jacoby (1994:273) stated;

> Scambler has commented that the ways in which individuals cope with their epilepsy are complex and as yet relatively under-researched, but it is clear from this and other studies that the psychological and social repercussions of epilepsy are not simply a function of its severity and further studies are required to elucidate the relationship between them.

Baker et al (1999) completed a study on stigma relating to epilepsy in a European sample. Participants consisted of 5,211 people over 16 years with epilepsy from 15 countries in Europe. This study found that 51% of participants had feelings of stigma related to their epilepsy. Baker et al (1999:103) state

> In our study, questions that probed psychosocial issues and their relation to feelings of stigma included "worry about epilepsy," "feelings about life as a whole," and patient-perceived scores on the impact of epilepsy scale. Worrying "a lot" about epilepsy was reported by more than twice as many of the respondents reporting stigmatisation when compared with those reporting no stigma at all.

Further, this study found significant differences between countries in relation to perceived stigma, and highlights the need to assess both clinical and non-clinical factors in understanding the stigma of epilepsy (Baker et al, 1999). Further, Dilorio et al (2003) completed a study on the association of stigma with self-management and perceptions of health-care among adults with epilepsy in the U.S.A. Participants consisted of 314 people with epilepsy who completed three assessments each assessment being three months apart. Dilorio et al (2003:264) states

> The results of this study suggest that stigma does indeed have an influence on health-related functioning and that this association is mostly negative...we found that stigma associated with having epilepsy is similar for men and women and across ethnic/racial groups.

Baker (2002) sought to determine the contribution of clinical, demographic, and psychosocial variables to the stigma of 6000 adults from ten European countries. Almost half of participants reported difficulty accepting their diagnosis of epilepsy. Seventeen percent of participants reported feeling stigmatised because of their condition. Baker (2002) found that seizure frequency, knowledge and duration of epilepsy, and seizure type were factors predictive of stigma but that the impact of these factors varied depended on the country. Paschal et al (2007) completed a study in the U.S on epilepsy patient's perceptions about stigma, education, and awareness. Participants consisted of 165 people with epilepsy, 62% female and 38% male. Almost 42% of participants reported the belief that the general public had negative feelings in relation to epilepsy while 41% believed that this negatively affected them. Another finding was that 20% reported denying having epilepsy at some point in their lives.

Paschal et al (2007:7/8) state

> ...65% of the respondent sample also indicated the belief that they would experience reduced epilepsy-related stress and problems if the public was better educated about the condition...as this study demonstrates, individuals affected by epilepsy are not only aware of the stigma their condition has in the broader community, but also believe that educational campaigns can help ameliorate stigma, negative self-image, and the stress they feel in their own lives.

According to Baxendale (2007) movie characters with epilepsy are commonly depicted as mad, dangerous and with demonic possession. Although this portrayal may contribute to the stigma of people with epilepsy even more dangerous is the incorrect appearance and treatment of seizures. This study examined the prevalence of belief in common cinematic epilepsy myths among internet users in the 21st century. Participants included all staff and students at University College London and resulted in 4,605 responses. Four myths were examined within this study; calling an ambulance, put something in seizing person's mouth, foaming at the mouth and violence in seizures. 58% of respondents would call an ambulance immediately if they witnessed a seizure, while 33% reported they would put something in the seizing person's mouth. Approx 3% believed they would become violent during a seizure. 46% of respondents believed the foaming myth. However, almost half of respondents know someone with epilepsy and this had a significant effect on the results.

Baxendale (2007:196)

> ...fictional movie characters with epilepsy continue to perpetuate a number of myths about the condition. These myths appear to be fairly widely held by the general population, particularly among those who have never witnessed an epileptic seizure, suggesting that people with epilepsy continue to be at risk of physical harm from one in three misguided members of the UK public who may attempt to put something in their mouths during a seizure.

In conclusion, it is apparent that there are a number of social impacts which may affect quality of life for people with epilepsy. Firstly, studies show that people with epilepsy have a higher prevalence of social problems. Secondly, educational underachievement is common in people with epilepsy. There are implications not only for parents of children with epilepsy but also for teachers and schools. Thirdly, another area in which people with epilepsy feel affects their quality of life is employment; studies suggest there are still misconceptions among employers with regard to epilepsy. Fourthly, driving restrictions for people with epilepsy can lead to job restrictions, feelings of dependency, school and other social restrictions.

Finally, stigma is still an issue for people with epilepsy. Studies also suggest that 'disclosure' is an issue, with some people hiding their condition from their employers. The next section of this chapter endeavours to provide an overview of quality of life and psychological impacts for people with epilepsy.

2.7 Quality of life and psychological impacts for people with epilepsy

Quality of life and psychological impacts of epilepsy refer to aspects of well-being for the person with epilepsy (Camilleri-Brennan & Steele, 1999). These impacts can include exercise and emotional well-being, adjustment to the diagnosis of epilepsy, depression & mood disorders and difficulties relating to memory and concentration. Arnston et al, (1986) cited in Roth et al (1994:1248) state

> The unpredictable seizures that intrude on the lives of epilepsy patients often can have serious and lasting emotional effects. In addition to the seizures themselves, worries about the possibility of seizures and the reactions of others to seizures compound the stressful nature of epilepsy. Considering these factors, together with the lifestyle limitations and socioeconomic hardships that often accompany epilepsy, it is not surprising that emotional difficulties are most often cited by adults with epilepsy as being the "single greatest problem" they encounter.

Naess et al (2007) assessed psychological well being of people with epilepsy in a Norwegian sample. A postal questionnaire was completed by 597 members of the Norwegian Epilepsy Association (NEF) aged between 16 and 87 years. The questionnaire consisted of eight items tapping symptoms of nervousness and depression. This study found that seizure frequency was closely linked to psychological distress and life satisfaction. It also found that side effects of medication such as tiredness and concentration problems had the strongest impact on psychological well being. Factors such as age, gender and education were not significant in the findings of this study. Exercise and emotional well-being for people with epilepsy will be discussed in the next sub-section.

2.7.1 Exercise and Emotional Well-being

In relation to exercise previously people with epilepsy would have been advised to avoid specific activities due to possible health implications such as swimming and cycling (Roth et al, 1994). However, in recent years people with epilepsy are generally being advised as to the advantages of leading active lives, although some people are still being misinformed with regard to this.

Roth et al (1994) assessed exercise participation levels of adults with epilepsy in order to establish whether active patients showed better emotional adjustment than inactive patients. This study also assessed the effects of stressful life experience and recent seizure frequency. The authors used simple t-tests to compare the active group to the inactive group and found that the active group reported considerably lower levels of depression than the inactive group. The active group also showed better psychosocial adjustment, and reported fewer barriers to exercise, while the inactive group were more likely to have had experienced a seizure while exercising and 15% of these had been advised to avoid 'most types of exercise'. This study supported the findings of previous studies such as Whitman and Hermann (1986) and Blumer (1991) in that it showed that adults with epilepsy are prone to considerable problems with depression and general emotional distress. Roth et al (1994:1254) state

> ...exercise and emotional adjustment appear to be directly linked in a relatively simple and beneficial way. This link may provide a potentially useful advance in our understanding of the ways in which emotional well-being might be maintained in adults with epilepsy.

The next sub-section of this chapter will discuss understanding of and adjustment to the diagnosis of epilepsy.

2.7.2 Understanding of and Adjustment to epilepsy

Appolone (1978:139/140) states

> Epilepsy has a legacy of frightening misconceptions, social stigma, and shame, which exacerbates the normal anxiety and confusion that parents feel upon learning that their child has a chronic health problem. Furthermore, witnessing a grand mal seizure is a dramatic and fear-provoking experience for the observer. For the parent, it can be terrifying. The emotional impact of that event may significantly alter parental management of the child henceforth.

A diagnosis of epilepsy can lead to social and quality of life problems which can be greater challenges than its clinical severity (Jacoby & Austin, 2007). Further, Jacoby & Chadwick (1992) suggest that adjustment to the diagnosis of epilepsy is fundamental to the person's well-being and if adjustment is dealt with appropriately it may help eradicate the feeling of stigma. In other words adjustment to the diagnosis of epilepsy is of paramount importance.

One of the peak times in which epilepsy is most likely to occur is in childhood. There are many issues relating to children with epilepsy including the impact on parents and siblings and the effect this can have on a family's lifestyle. A diagnosis of epilepsy in a child can be a very difficult time and can lead to parents having feelings of grief and guilt, alongside fears and doubts about the future. Overprotection can have a huge impact not only on the quality of life of a child with epilepsy but also on all family members. West (1986) cited in Baker & Jacoby eds. (2000:126) states

> ...that parents attempts to conceal their child's epilepsy and the parents perceived stigma from the illness had a negative impact on the child's sense of identity.

In addition, Austin et al (1998) evaluated psychosocial care needs of parents of children with new-onset seizures. Participants consisted of 100 parents of children aged between 4 and 14 years. The authors found that parents required more information and support. In particular mothers worried extensively about implausible incidents such as brain damage, addiction to anti-epileptic medication and death. However, children worried about the social facets of epilepsy. This was highlighted further by Jacoby (2002:13) who stated that

> Similarly, Schneider & Conrad reported that the parents of people with epilepsy whose own reaction was negative practiced what the authors referred to as "disabling talk" with their children, during which the parents focused on the restrictions faced by people with epilepsy and coached their children to conceal their condition from others.

A study completed by Jacoby et al (2004) assessed public attitudes and knowledge relating to epilepsy in the U.K. Participants consisted of >1,600 members of the general public. Favourable attitudes in relation to epilepsy was expressed in those more familiar with epilepsy and those from higher upper classes but overall attitudes toward epilepsy were not unlike those reported in other countries in the developed world. The sample of the general public seemed well informed about epilepsy in relation to causes, seizures and anti-epileptic medication. However, they seemed less informed in relation to prevalence and a significant number of the respondents categorised epilepsy as a mental problem rather than a physical or health problem. Other negative findings included; a quarter of the sample agreed that people with epilepsy have more personality problems and more than half agreed that people with epilepsy are treated differently by society.

Baker et al (1999) assessed patients understanding of and adjustment to epilepsy. The sample within this study was not random. Rather, respondents were from epilepsy support groups from four European countries; England, France, Germany and Holland. However, interesting conclusions were achieved. For instance, the area of medication revealed some gaps in knowledge and the lack of understanding with regard to the aetiology of epilepsy were evident. Implications for people with epilepsy were apparent due to the misunderstanding that epilepsy was a direct result of brain damage (Baker et al 1999). This study suggested a need for specific subgroups to be targeted. In addition, Jarvie (2001:23) states

> There can be little doubt that successful adjustment to epilepsy is dependent on people with epilepsy having a good understanding of their condition and its treatment. However, there is a growing body of evidence which has shown that there is significant ignorance with regards to the purpose and results of diagnosis, the causes and consequences of seizures and the purpose and possible side effects of medication. There also appears to be considerable dissatisfaction with the provision and availability of epilepsy related information.

This highlights the need for every person diagnosed with epilepsy to obtain appropriate and reliable information relating to their epilepsy as soon as possible after the diagnosis is made. The Neurological Alliance of Ireland (NAI) published standards of care relating to epilepsy and highlights the above point stating (2000:12)

> People with neurological disabilities have difficulty accessing specialist services because of the limited number of neurologists and other specialists in Ireland. For some people, especially those with rare conditions, it may take some time for accurate diagnosis to be confirmed, especially in the early stages. These delays are further exacerbated by the, limited availability of specialist services in certain geographical areas, and lead to unavoidably long waiting times for initiation of diagnostic investigations. This is of particular relevance at the time of initial presentation, when symptoms may be difficult to interpret, and subject to misdiagnosis…all people should have a reasonable expectation that their neurological condition will be efficiently investigated, diagnosed and treated by a relevant specialist.

Velissaris et al (2007) completed a study assessing the psychological adjustment of 85 people with epilepsy following a newly diagnosed seizure in Australia. The authors found that participants tried to address the cause of their seizure but that this often lacked a medical basis and they denied the possibility of having more seizures saying that the initial seizure was an isolated incident. Velissaris et al (2007:230) state

> Patients with a pervasive loss of control were affected both physically and psychologically, as the seizure deeply exposed them to their own vulnerability. This experience appeared to precipitate extensive efforts to restore perceived control, including behavioural changes in life and personal domains not directly related to the seizure.

2.7.3 Depression & Mood Disorders

According to Grabowska-Grzyb et al (2006:411)

> Depression in patients with epilepsy is a serious medical and social problem since it afflicts almost one half of all patients treated in epilepsy referral centres. It seems to be correlated with certain types of epileptic seizures, with high frequency of seizures....and lack of occupational and social activity.

This study was based in Poland and its aim was to find possible risk factors for the development of depression in patients with epilepsy. The study consisted of 117 females and 86 males with no prior diagnosis of depression. The authors found that lack of employment/education was the only factor which was statistically significantly correlated with depression. The authors also found that the non-depressed group had more patients at third level education, although this was not statistically significant. However, this may confirm the theory that lack of professional activity contributes to mood disorders and not the other way around which has been suggested by some authors. Another issue raised in this study indicated that the type of seizure experienced by patients seemed to play a role in contributing to the occurrence of depression. Further, Grabowska-Grzyb et al (2006:415) state

> ...our study did not identify any correlation between gender, age, or family history of depression and other neurological disorders and the risk of depression in the patients with epilepsy.

Data on the prevalence of depression in patients with epilepsy vary. Prueter & Norra (2005) suggest an incidence of 30% - 40%. Prueter & Norra (2005:25/26) states

> For many patients, epilepsy, per se, significantly limits the quality of life. A depression that is unrecognised and untreated worsens the quality of life for these patients. Consequently, therapy for depression is absolutely needed to improve the quality of life of these patients.

This was also highlighted by Boylan et al (2004) who found that depression was a strong predictor of quality of life of people with refractory epilepsy. This study suggests that depression may be inadequately prioritised for those with refractory epilepsy (Boylan et al, 2004). Bishop & Hermann (2000:115) state

> It is generally accepted that the increased prevalence of depressive symptoms among persons with epilepsy is due not to a single factor, but to the complex combination of factors involved in having, treating and living with a chronic and unpredictable neurological disorder.

Further, according to Cramer (2002) although studies have shown a high incidence of depression in people with epilepsy, the number of people actually treated is low.

Gilliam et al (2004:28) reiterates this point stating

> Although depression appears to be highly prevalent in epilepsy and has significant consequences, available data indicate that most patients with depression are not screened or treated.

An Italian study completed by Beghi et al (2004) assessed the prevalence of depression, the factors associated with depression and the health-related quality of life of women with epilepsy of childbearing age. Forty neurologists were asked to enrol ≤20 women with epilepsy aged between 18 and 55 years. The total number of participants was 642. Mendez et al (1993) suggest that depression is more common in epilepsy than with other chronic conditions. This was confirmed within this study which found; overall depression reported by 37.7% of women. Factors that were associated with depression in this study included unemployment or being a housewife; the presence of active epilepsy; and the presence of accompanying treatments. Beghi et al (2004:69) state

> ...the high correlation between presence and severity of depression and extent of impairment of physical, social, and emotional HRQOL domains in this study is worth noting. This finding supports the assumption that impairment of mood and overall quality of life in women with epilepsy of childbearing age reflects the role of emotional, physical, psychological, and social implications of the disease.

According to Goldstein (2000:240)

> It is also widely accepted that people with epilepsy are at risk of having cognitive impairments, especially in the domains of memory and concentration. Whether these are a result of the combination of the.....seizure activity, side effects of medication or associated mood disorder, they may well impact on people's everyday lives and restrict their educational and work opportunities.

Moreover, Johnson et al (2004) highlighted issues relating to depression whereby their study indicated that mood and anxiety were powerful factors which should be considered in HRQOL assessments in epilepsy. The authors of this study recommend prospective research to be completed to assess the degree to which treatment of depression/anxiety may improve HRQOL. Loring et al (2004) also suggest that symptoms of depression and seizure worry are the most important factors affecting quality of life in people with epilepsy. Memory and concentration difficulties for people with epilepsy will be discussed in the next sub-section.

2.7.4 Memory and concentration difficulties

The presence of memory problems in people with epilepsy is well recognised and is one of the main issues people with epilepsy would seek help for (Baker et al, 2006; Ponds et al, 2006). A large part of memory function is located in a specific area of the brain known as the temporal lobe. According to Baker (2006) there are many reasons people with epilepsy may have memory difficulties such as an underlying brain tumour/lesion. Some anti-epileptic drugs may interfere with memory function as they affect the speed at which the brain can process information. Further, in order for memory to work properly the brain needs continuous self-monitoring and this can be disrupted during a seizure. Other impairments can also affect memory functioning including an attention problem, a language problem, a visual/spatial problem, anxiety, depression and sleep disturbances. A neuropsychological assessment can determine where exactly memory difficulties lie and, therefore, focus on memory enhancement strategies that are appropriate to the individual. Memory difficulties can be an issue in a person with epilepsy quality of life as it can make it difficult to cope with everyday life. It can affect relationships and create anxiety (Baker, 2006).

2.7.5 Pseudo-epilepsy

Pseudo-epilepsy is also known as non-epileptic seizures (NES). This means that the person does experience seizures. However, the experience does not involve any abnormal brain activity when EEG monitoring is completed. A study completed by Mazza et al (2006) looked at the complexity and severity of NES. The authors evaluated three samples; patients with NES, patients with epilepsy and a control sample. The authors found that NES typically manifests between 20 and 30 years of age and approximately two-thirds of patients with NES are men. They also found a link between traumatic experiences and the development of NES. According to Walker & Shorvon (1999) it is difficult to distinguish NES from true epileptic seizures. NES are usually involuntary and occur without conscious motivation. The person has little control over these 'attacks'. They can be similar to an emotional outburst and often have a deep rooted emotional basis. NES do not respond to anti-epileptic medication. Usually NES is difficult to differentiate from an epileptic seizure and requires hospitalisation for observation.

In conclusion, the literature suggests there are a number of psychological impacts which may affect the quality of life of people with epilepsy. Firstly, seizure frequency and medication side effects are closely linked to psychological distress in people with epilepsy. Secondly, people with epilepsy that are physically active show better psychological adjustment and report lower levels of depression than inactive people with epilepsy. Thirdly, studies suggest that adjustment to the diagnosis of epilepsy is fundamental to a person's overall well-being. Finally, studies have found a high incidence of depression in people with epilepsy. However, the number of people with epilepsy actually treated for depression is low. The next section of this chapter endeavours to provide details on universal impacts and quality of life for people with epilepsy.

2.8 Universal quality of life impacts for people with epilepsy

Universal quality of life impacts consist of common threads which overlap with physical, social and psychological impacts for people with epilepsy but may also have implications for social and health policy. These include neurological services, support services, epilepsy information and the economic aspects of epilepsy.

2.8.1 Neurological services

A study completed by Neligan et al (2006) assessed GP attitudes to a wide variety of issues concerning the management of patients with epilepsy, particularly awareness of new anti-epileptic drugs and their side-effects. This study was carried out in Cork and Kerry and questionnaires were distributed to 175 GPs. The majority of GPs felt that seizure prevention was the most important factor for people with epilepsy while the second was the person maintaining their job. Overall within this study GPs' perception of people with epilepsy remains negative, with a significant impact on patient's occupation, mood and quality of life and is illustrated in the following table.

Table 2: Illustrates percentage of GPs who felt epilepsy has a negative impact on a patient's occupation, mood and quality of life

	N	%
Occupation	157	89.7
Mood	133	76
Quality of life	154	88

Source: Neligan et al (2006:53)

Due to the waiting time for appointments to see consultant neurologists, almost a quarter of GPs would begin treatment after a first seizure. This study suggests that greater communication between GPs and neurological services is essential. This will allow information in relation to advances and changes in clinical neurological services to be accessible to GPs and so lead to the successful management of people with epilepsy (Neligan et al, 2006).

A study completed by Frith et al (1994) assessed GP attitudes and management of epilepsy in Sydney (a similar study had been completed ten years previous). According to Frith et al (1994) GPs are usually the first contact in the diagnosis of a person with epilepsy. There empathy, explanation of the condition and assistance in the preservation of normal quality of life is essential to the adjustment of the person to their condition. The study concluded that the stereotyped perceptions of GPs identified in the previous study have improved. However, some have remained negative. For instance, GPs perceived people with epilepsy as having more emotional and relationship problems. This view has been supported by other authors (Callaghan et al, 1992, Wada et al, 2004, Crawford et al, 2006). The study by Frith et al, (1994) shows a marked improvement in the perceptions of GPs in relation to people with epilepsy are due to a decade of educational promotion regarding epilepsy. In most cases GPs referred patients to neurologists for initial management but also see themselves as having role in the continuing care for people with epilepsy while also providing psychosocial support. In contrast, Wagner et al (1997) cited in Baker & Jacoby (2000:59)

> Looked at the routine use of QOL questionnaires for patients with epilepsy and found that though consultation time was lengthened and doctors felt that such measures provided new information about the patient, they did not alter their management of the patient and patients did not report any increase in satisfaction.

As stated previously, once a diagnosis of epilepsy is made the patient is usually referred to a consultant neurologist. Given that it is estimated up to 40,000 people in Ireland have some form of epilepsy it is apparent that appropriate services are essential. It is estimated that people with neurological conditions have to wait up to two years for an appointment, which can have an enormous effect on their quality of life.

This affects both the public and private sector and is reflective of the fact that there is a huge lack of neurologists in Ireland and the fact that changes in demographic and therapeutics are not being planned for (Delanty, 2006).

Baker (2000:182) states

> For healthcare providers, rendering patients seizure-free with minimal medication side-effects and subsequently improving their quality of life is also likely to be seen as the most important target of the management and treatment of epilepsy. However, while freedom from seizures is the ideal, it is not always achievable and patient's experiences of living with their continuing condition and of its treatment should be of equal concern.

The following table illustrates the population per Neurologist Specialist in a number of various countries.

Table 3: Illustrates the population per Neurologist Specialist

Country	Population per Neurologist
Australia	51,900
Belgium	71,000
France	39,300
Germany	41,000
Greece	21,200
Ireland	300,000 Now 210,000
Japan	63,000
U.K	164,000
U.S.A	26,200

Source: Population data WHO 2000 cited on www.wfneurology.org:

The above table illustrates that Ireland has the lowest number of Neurology specialists. Moreover, with regard to neurological services in Ireland, the Comhairle na nOspideal report (2003) recommended the setting up of three new regional neurology units in Limerick, Sligo and Waterford alongside provision for outpatient clinics and consultations to other hospitals in their areas. The report also recommended a target of 39 consultant neurologists to serve the population of Ireland i.e. 1 per 100,000, with an interim target of 29. At present there are a total of 19 neurologists in Ireland. This falls far short of the recommendations of the 2003 report. Currently in the U.K there is one neurologist per 164,000. The census of Ireland in April 2006 shows there has been an increase of 8.1% in the last four years in the population of Ireland.

Taking into account this increase in conjunction with the target of one consultant neurologist per 100,000 the recommended figure of neurologists would be 42.

There is a major lack of neurologists, epilepsy specialists, and other professionals involved in the care of people with epilepsy. The gaps in the provision of neurological services within Ireland can adversely affect the quality of life of people with epilepsy.

A policy document from the Department of Health in the U.K 'The Expert patient: A new approach to chronic disease management for the 21st century' (2001) points out that research in North America and Britain shows that patients need not only be recipients of care but also be key decision makers in their treatment. This may be achieved through patients receiving extensive knowledge about their condition. This may result in the empowerment of patients to take control of their treatment and care in conjunction with health and social care providers. This may benefit the quality of their care and ultimately their quality of life.

2.8.2 Support services

Brainwave, the Irish Epilepsy Association is a member's organisation which provides information, advice, counselling, aids, and training and advocacy services for people with epilepsy in Ireland. However, it should be noted that not everyone with epilepsy is a member of Brainwave and there are no official statistics of how many people in Ireland have epilepsy. This may impact on the organisations ability to support and offer appropriate facilities to people with epilepsy. Our current statistics are approximated from the UK and USA.

A study completed by Thompson & Upton (1992) assessed the impact of chronic epilepsy on the family. The authors sought to assess the levels of practical and personal support available to families within the study and how these can affect the psychological well-being of persons caring for a relative with epilepsy. Thompson & Upton (1992) suggest that family member's perceptions and the severity of the epilepsy are important predictors to the psychological morbidity which can be apparent in family members.

This study found that there are increased levels of psychological stress and social problems in families where an adult member has chronic epilepsy and the high level of dissatisfaction with aspects of social life can be seen as an indicator of diminished quality of life. This study also found that most respondents were unaware of the supports and resources available to them. In addition, Beech (1992:133) states

> It is reasonable to assume that family attitudes, approaches and behaviours are to some extent shaped by a sound level of understanding of the disorder.

2.8.3 Epilepsy information

Hart et al (1995) found that the most common area of dissatisfaction for people with epilepsy in the U.K was lack of patient information about epilepsy. Further, Chappell et al (1998) also found lack of information about epilepsy and its implications to be poor. Participants within this study found that they 'rarely' or 'never' received enough information about their epilepsy. A study completed by Long et al (2000) assessed epilepsy patients' knowledge of their disorder. The questionnaire was completed by 175 patients with epilepsy over 16 years, newly referred to a comprehensive epilepsy program in the U.S. The authors found that patients were not knowledgeable about their condition. This was despite patient's age, educational background, or the number of years they had epilepsy. The assumption that older patients with a long history of epilepsy would be more informed as to their condition was not supported by this study. Long et al (2000:727) stated

> Thirty percent believed that epilepsy is a mental disorder or contagious. Forty-one percent believed it is appropriate to place an object in a patient's mouth during a seizure to prevent injury.

Further, the authors highlighted the need for educational intervention for people with epilepsy with specific regard to injury prevention and issues such as driving regulations and the legalities of employment (Long et al, 2000).

Poole et al (2000) completed a study in the U.K which assessed 2394 patients with epilepsy satisfaction with care, care preferences and information provision. Generally, patient satisfaction was high. However, younger patients and those with severe epilepsy were more satisfied and preferred hospital care. This was due to doctors within the hospital knowing more about epilepsy. Older patients reported the opposite and appeared more satisfied and preferred primary care (GP). This was due to their GP knowing them and it was seen as more personal care.

Although satisfaction was high, in terms of information two issues were highlighted within this study. Firstly, respondents felt that their care was not shared between hospital and GP. Secondly, respondents especially the elderly felt that the provision of information was poor.

Information is a key factor in promoting health and well being for people with epilepsy. A tragic example of the consequences of lack of information in all areas relating to epilepsy occurred in Scotland in 1998. The Findlay inquiry investigated the death in 1998 of a seventeen-year-old girl with epilepsy. A fatal accident inquiry is used to investigate any death where there is possible public interest in learning lessons to prevent similar deaths in the future. The inquiry reported in September 2002, concluded that the young woman died as a result of an epileptic seizure, during which she stopped breathing. It also found that the hospital and family GP had not provided her with a co-ordinated care plan and `there were many other failures such as not providing information to the young woman and her family about her epilepsy, medication, prognosis and not informing them of the possibility of sudden unexplained death in epilepsy and the risk factors associated with it (Epilepsy Bereaved, 2002).

2.8.4 Economic aspect of epilepsy

The ILAE (International League against Epilepsy) commission on economic aspects of epilepsy was established in 1994. The objective of which, Beran et al (1994:1359) states

> ...was to advise ILAE executives on the measurement of economic costs and models of care in the management of epilepsy.

The commission worked on the cost of epilepsy in the United States and IBE (International Bureau for epilepsy) study of the cost of epilepsy in Europe. It also considered epilepsy as an economic burden for the individual person. Evaluating economic factors was a tool with which to argue for improved patient care. Beran et al (1997:1359) states

> The financial burdens of illnesses such as epilepsy are receiving considerable attention with regard to both individual patients and society as a whole. Rising health expenditures and competing demands for resources dictate the need for economic evaluation and proof of efficiency to justify the support for any treatment option. Therefore, optimal care for those with epilepsy will depend largely on balancing outcomes with economic determinants.

According to the National Institute of Clinical Excellence epilepsy misdiagnosis rates in the U.K are between 20%-31% and result in an annual cost of approximately £160 million (Joint Epilepsy Council, 2005).

In relation to Ireland the possibility of calculating the cost of illness with regard to epilepsy is, to date, extremely difficult. In order to do this, prevalence and incidence and epidemiology data are essential in determining cost of illness (Beran et al, 1997). However, Ireland to date does not have prevalence or incidence statistics.

In conclusion, universal quality of life impacts for people with epilepsy consist of a number of factors. Within the Irish context it is apparent that there is a major lack of neurologists and other professionals which results in huge gaps in the provision of services for people with epilepsy. In addition, the lack of official statistics regarding epilepsy highlights the difficulty in providing effective service provision for people with epilepsy.

2.9 Conclusion

To date there are no reliable statistics of the prevalence or incidence of epilepsy in Ireland. Research is currently being conducted in this area by UCD. It is apparent that little research has been completed in the area of quality of life for people with epilepsy within Ireland and further research is warranted given the many implications epilepsy may have on the individual.

As outlined in this chapter there are many implications outside of the medical field for people with epilepsy which relate to quality of life that need to be addressed. Important areas of concern for people with epilepsy which have been evident from the review of relevant literature are in the areas of physical, social, psychological and universal domains.

Within the physical domain it is apparent that there are numerous issues that may affect quality of life for people with epilepsy. Areas of importance highlighted include medication, seizure frequency, physical fitness and accidents. Within the social domain areas of importance highlighted include education, employment and stigma.

Within the psychological domain issues highlighted include exercise and emotional well-being, adjustment, depression and memory and concentration difficulties. Universal quality of life impacts for people with epilepsy are common threads linking the above three domains which may also have implications for social and health policy. Areas of concern highlighted include neurological and support services and epilepsy information. From the review of the literature it is clear that there are many factors which need to be taken into account when assessing quality of life for people with epilepsy.

Finally, quality of life research places the person with epilepsy's viewpoint centre-stage. The disadvantage surrounding this research lies within the lack of a universal definition and the subjective nature of quality of life assessment. Jacoby (2000:53) state

> One of the major criticisms levelled against quality of life assessments is that they are subjective and therefore not 'hard' scientific data. This has been vigorously challenged by writers such as Fallowfield (1990) who has described quality of life as the vital 'missing measurement in health care'.

3.0 Research Methodology

3.1 Introduction

The main focus of the research is on exploring quality of life issues for adults with epilepsy living within the Western Region of Ireland. The researcher was interested in the topic of epilepsy from years of experience working with people with disabilities the majority of whom also had epilepsy. The researcher also has a keen interest in the area of research which developed from the completion of a dissertation in the final of her degree.

This study aims to ascertain the implications of having epilepsy and explore the quality of life issues for people with epilepsy, specifically those living in the Western region of Ireland. From this a number of objectives will be achieved. These objectives include

- To highlight epilepsy as a public health priority among local and national government boards and agencies.
- To highlight specific quality of life impacts for people with epilepsy.
- To promote the exchange of knowledge between all disciplines in relation to physical, social and psychological impacts of epilepsy; and
- To highlight the need for a national database regarding the number of people with epilepsy in Ireland.

The main reason for choosing the Western Region of Ireland; which is divided into, the West (Roscommon, Mayo, and Galway), the North West (Sligo, Leitrim, Donegal) and the Mid West (Limerick, Clare, Tipperary) was due to the apparent lack of services for people with epilepsy living within the region.

Quality of life assessment is an approach which unambiguously establishes the patient at the centre of attention. It is especially relevant to the elderly and people with illnesses where the preservation of quality of life rather than cure may be the main goal of treatment (O Boyle, 1997). Jacoby & Baker eds. (2000:1) state

> A person with epilepsy faces a whole range of clinical uncertainties, over the diagnosis, over whether and when seizures will occur, over the nature of seizures and how best they can be controlled and over whether or not they will ultimately remit....the unpredictability of the nature and course of epilepsy is a key factor that impacts on the quality of life of people who develop it.

This suggests that for people with epilepsy medical care alone may not be enough to provide effective service provision. There have been numerous studies and research completed on the clinical aspect/treatment of epilepsy. Only in recent years have quality of life issues for people with epilepsy been explored and researched. Many authors conclude that the main domains within quality of life consist of physical, social and psychological (Camerilli-Brennan, 1999). These three areas will be explored during the course of this research. A fourth area will also be explored, universal quality of life impacts for people with epilepsy. Exploring these issues will significantly increase our understanding of epilepsy while raising awareness of the key issues surrounding this condition in order to develop more adequate service provision taking into account all aspects and issues which may arise.

In order to carry out this research, the researcher will employ triangulation. Bryman (2004:458) states

> This approach to multi-strategy research occurs when the researcher cannot rely on either a quantitative or a qualitative method alone and must buttress his or her findings with a method drawn from the other strategy.

According to Sarantakos (1988:169) triangulation allows the researcher to;

- obtain a variety of information on the same issue
- use the strengths of each method to overcome the deficiencies of the other
- achieve a higher degree of validity and reliability; and
- overcome the deficiencies of single-method studies.

The use of multiple research methods within this research will consist of literature review, qualitative and quantitative research. The first section of this chapter describes the theoretical framework and guiding hypotheses of the research. The second section describes the research strategy. The third section explains quantitative and qualitative research. The fourth section describes the research design incorporating details on the focus group, questionnaire and interviews. The fifth section outlines the research process incorporating details on the sample of participants, response rate, pilot questionnaire and data analysis. The sixth section describes the ethical considerations of the research. Finally, the last section describes the strengths and limitations of the research.

3.2 Theoretical Framework

The literature review consists of a review of existing literature in relation to epilepsy. It explored current knowledge and understanding of quality of life issues in epilepsy and concentrated on four specific areas. Firstly, quality of life and physical impacts for people with epilepsy incorporating issues such as medication, seizure frequency and physical fitness. Secondly, quality of life and social impacts for people with epilepsy incorporating issues such as employment, driving regulations and stigma. Thirdly, quality of life and psychological impacts for people with epilepsy incorporating issues such as understanding of and adjustment to epilepsy, depression, mood disorders and memory and concentration difficulties. Fourthly, universal quality of life impacts for people with epilepsy incorporating issues such as neurological and support services and epilepsy information. Aldenkamp (2000:27) states

> The enormous body of research that has been carried out over a period of more than a century provides ample evidence to illustrate that people with epilepsy, as a group, have more cognitive, behavioural and emotional problems than control populations of healthy subjects. In some individuals such problems may be more debilitating than the seizures themselves.

Further, Devinsky et al (1995) cited by Steinbuchel (2000:66) points out

> That it is a subjective concept the patient is the expert on his or her quality of life, and maintains that 'the ways in which the disorder and the seizures impact on a person's life are as individual as fingerprints'.

One of the first issues in quality of life research is in the lack of a universal definition. The researcher chose the definition of quality of life laid down by the WHOQOL group due to the nature of the research topic and because it emphasises quality of life as subjective and multidimensional. Moreover, Thompson et al (1993) cited by Bishop et al (2003:226/7) stated

> The impact of epilepsy on a person's life is multidimensional and can span a range of functional and psychosocial domains. Along with the potential physical and cognitive problems associated with seizures, epilepsy has been associated with psychological and emotional problems, social isolation, and problems concerning education, employment, family life, and leisure activities.

Rapley (2003) suggests that quality of life assessment has become important in service design, delivery and evaluation in the areas of medicine and social care and can even affect decisions relating to service and intervention programmes.

Given this, it would be imperative that people with epilepsy themselves should be involved in the development of the tool to be used in the assessment of their quality of life. However, Askoy cited in Rapley (2003) suggests that quality of life cannot be measured accurately or reliably but does state that individual's lives should be respected and we have a duty to try and improve their condition as far as possible. In brief, quality of life research places the person with epilepsy's viewpoint centre stage. Fallowfield (1990) cited by Jacoby (2000:53) describes

> ...Quality of life as the vital 'missing measurement in health care'.

3.2.1 Guiding hypotheses

This research was an exploratory piece. It was guided by a number of hypotheses that emerged through the review of the literature. The guiding hypotheses in this research project were grounded by a number of theories. Firstly, quality of life issues are under-researched in Ireland. Secondly, there are real physical, social and psychological impacts for people living with epilepsy. Thirdly, epilepsy impacts on the quality of life of those living with the condition. Overall these impacts appear to be negative. However, this may be subject to the context of the individual.

3.3 Research Strategy

Initially the proposed research was going to be a baseline study of people with epilepsy in Ireland. In the early stages of this Strand I initiative it was discovered that a prevalence and incidence study had already begun elsewhere in the country. Although this meant a change of topic for the researcher it had actually laid the foundations for what would become the chosen area of research. The initial focus was on reviewing current literature on epilepsy. From this it became apparent that there is very little published research relating to epilepsy in Ireland with the main current research being on educational, medical and advisory provision for children with epilepsy in Ireland completed by Senior (2003). This led the researcher to delve more deeply into where there were gaps of knowledge relating to epilepsy in Ireland. One such area was quality of life in epilepsy. There have been numerous studies completed in this area in the U.K. and other countries. The researcher felt that the area of quality of life in epilepsy warranted further exploration within an Irish context in order to provide a basis for understanding these issues.

This, in turn, will serve as a basis to develop policies in the area. It also fits with the growing emphasis on user-knowledge, empowerment and the notion of the 'healthy citizen'.

One of the main difficulties apparent within quality of life assessment is the lack of a universal definition. However, there are numerous quality of life measurements existing. Baker & Jacoby eds. (2000:45) state

> The 1990s has seen publication of a significant number of QoL assessment tools for epilepsy...In a recent editorial, Hays (1995) concludes that we have now reached the point in epilepsy where we need to, 'focus efforts on evaluation, fine-tuning and applying the existing arsenal rather than proliferating' new QoL measures.

Given the above difficulties the researcher felt that exploratory research was warranted to gain more accurate information on quality of life issues for people with epilepsy. Although the research was exploratory it also had guiding hypotheses. This research was achieved through the use of both quantitative and qualitative research methods. Quantitative research was used as it allowed the researcher to elicit more detailed background information of a sample of people with epilepsy living in the Western region of Ireland which would not be achievable through qualitative means. According to Bryman (2004) many authors criticise qualitative research claiming it is too subjective but given that quality of life is often described as subjective this seemed to be an appropriate research tool, in that it allows the people with epilepsy to best describe areas in which their epilepsy affects their quality of life while also taking into account the views of professionals in the field of epilepsy. The following section of this chapter provides a theoretical explanation of quantitative and qualitative research.

3.4 Explanation of Quantitative and Qualitative Research

Quantitative research emphasises quantification in the collection and analysis of data. This method is deductive, in that, it entails the collection of numerical data; it attempts to illustrate a relationship between theory and research, while maintaining objectivism. Objectivism implies that social phenomena and their meanings exist independently and are beyond our control (Bryman, 2004). Bryman (2004: 63) states

> A great deal of quantitative research does not entail specification of a hypothesis and instead theory acts loosely as a set of concerns in relation to which the social researcher collects data.

When information has been collected it is then transformed into data by the researcher. This means that it is prepared to be quantified, in other words information is coded. Coding is a process which involves transforming the information gathered into numbers to facilitate analysis of the data.
This analysis then produces the findings of the research. The quantitative method of research employed in this research was a self-completion postal questionnaire.

Qualitative research emphasises words in the collection and analysis of data. It is a process of communication between researcher and participant whereby emphasis is on discovery and exploration. According to Sarantakos (1988:295)

> Qualitative research involves a dynamic process of gathering, thinking, evaluating, analysing, modifying, expanding, gathering further, and thinking again and so on.

Aveyard (2007:31) states

> The fundamental principle of all qualitative approaches is to explore meaning and develop understanding of the research topic.

Further, Holloway (2005:1) states

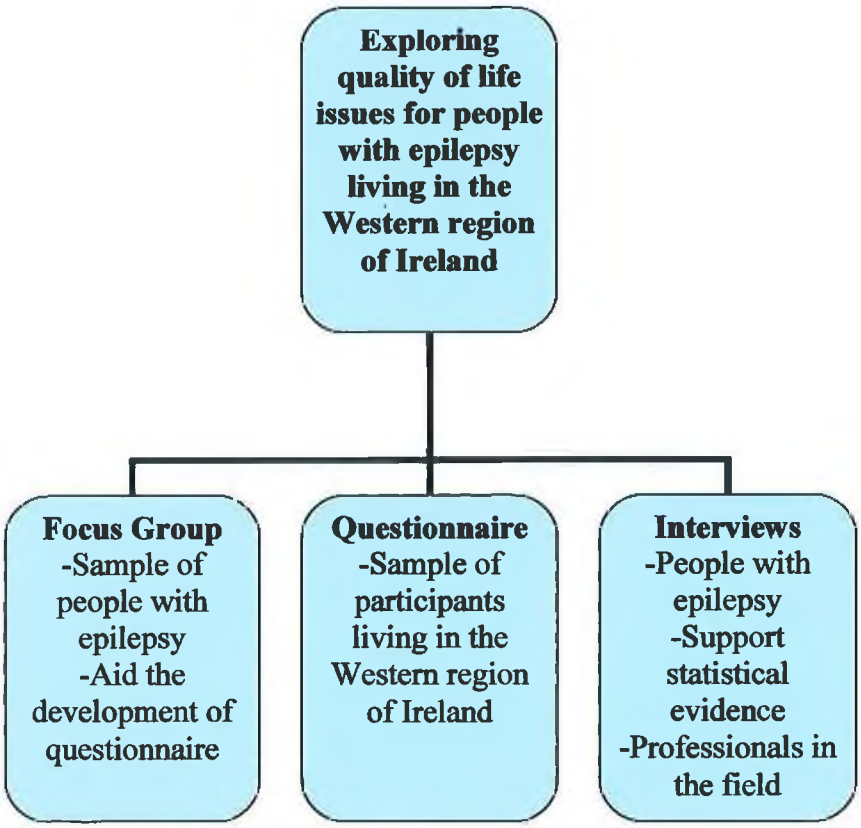
> Qualitative research can be an important tool in understanding the emotions, perceptions and actions of people who suffer from a medical condition.

The qualitative methods of research employed in this research were a focus group and interviews. The following section of this chapter provides an overview of the research design. It provides details on the focus group, questionnaires and the interviews.

3.5 Research Design

The following chapter outlines the design of the research and includes details on the focus group, questionnaires and interviews. The following figure illustrates the design of this research.

Figure 1: Illustrates the design of the research



3.5.1 Focus Group

The focus group technique is a method of interviewing a small group of people, usually 4-10. It involves discussion on a specific topic whereby the researcher can gather information on perceptions, attitudes, opinions and experiences of the individuals participating. Bryman (2004:346) states

> The focus group practitioner is invariably interested in the ways in which individuals discuss a certain issue as members of a group rather than simply as individuals. In other words, with a focus group the researcher will be interested in such things as how people respond to each others views and build up a view out of the interaction that takes place within the group.

Given the subjective nature of quality of life research a focus group was completed to aid the development of the self-completion questionnaire so that a sample of people with epilepsy had involvement in the content of the questionnaire and issues which they felt warranted further exploration within this research.

The focus group was held in the Institute of Technology, Sligo, as this was accessible and convenient to those participating. The participants consisted of four students with epilepsy living in the Western region of Ireland. All participants agreed to sign consent forms before the session began and the group session was tape recorded. The participants were given a 'topic guide' (see Appendix B). This guide included topics based on exploring quality of life for people with epilepsy, which were intended for discussion. These topics included physical, social and psychological and universal quality of life impacts for people with epilepsy. Participants were also encouraged to add any other comments or discuss any other issues which they felt were important. Participants were also given exit questionnaires at the end of the session (see Appendix C). The exit questionnaire consisted of a one-page list of questions to enable the researcher to gain general background information on the participants while maintaining confidentiality. This focus group assisted in the development of the questionnaire. As quality of life is a subjective phenomenon the researcher felt that it was important to gain insight into quality of life issues from a sample of people with epilepsy living in the Western region of Ireland. The questionnaire is further discussed in the next sub-section.

3.5.2 Questionnaire

The method in this research consisted of a self completion postal questionnaire (see Appendix D). According to Bryman (2004) the advantages of self completion questionnaires include they are cheaper and quicker to administer. There is absence of interviewer variability and they are convenient for respondents. The disadvantages include that the researcher cannot probe or prompt respondents. To a certain extent the researcher does not know who answers so the researcher cannot collect additional data. It is difficult to ask a lot of questions. There is a greater risk of missing data and there is usually a lower response rate.

The questionnaire within this research involved dividing quality of life impacts specifically related to people with epilepsy into four categories. The first category involved general questions which included background details of respondents such as gender, age and marital status. The second category involved physical impacts which included questions relating to general health, seizure frequency and medication.

The third category involved social impacts which included questions relating to education, employment and driving. Finally, the fourth category involved psychological (general well-being) impacts which included questions relating to memory, mood and concentration. The questionnaire was devised by the researcher and consisted of open-ended and closed questions, and a number of Likert scales. At the end of each section there were five statements where the respondent was asked to state their level of agreement with each statement. These statements and the five possible levels of agreement are called likert scales. According to Sarantakos (2005:250)

> Likert scales are widely used, particularly as a means for studying attitudes. The response categories range between two extreme positions divided into five points corresponding to a verbal-numerical scale.

The next sub-section of this chapter provides an overview of interviews.

3.5.3 Interviews

Interviews consist of verbal questioning as the main technique of data collection (Sarantakos 1988). Bell (1997:91) states

> A major advantage of the interview is its adaptability. A skilful interviewer can follow up ideas, probe responses and investigate motives and feelings, which the questionnaire can never do.

Further, Cohen (1976:82) cited in Bell (1997:92) states

> Like fishing, interviewing is an activity requiring careful preparation, much patience, and considerable practice if the eventual reward is to be a worthwhile catch.

There are numerous criteria for qualitative interviews. They consist of open-ended questions. Predominantly they are single interviews. The question structure allows for change in order or the adding of new questions. They allow for the adjusting of the interview questions to meet the goals of the study. The advantages of interviews include they are flexible. Usually interviews have a high response rate. The researcher has control over the environment, the order of questions and the identity of respondents. Interviews allow complex questions to be used. Finally, they can be of greater length and have the capacity for correcting misunderstandings. Disadvantages of interviews include they can be costly and can be time consuming. There is less anonymity and can be inconvenient.

Finally, they can be less effective in relation to sensitive issues (Sarantakos, 1988). The type of interview selected for this research will be discussed in the next sub-section.

3.5.4 Type of Interview

The type of interview used within this research was semi-structured, which consists of aspects of both structured and unstructured interviews. Open-ended questions were employed for the interviews. This method of semi-structured interviews was chosen for this research as questions are usually more general, it allows the researcher to vary the sequence of questions and it also allows the researcher to add further questions which may arise during the course of the interview (Bryman, 2004). Face-to-face interviews took place. Due to unforeseen circumstances two particular face-to-face interviews had to be cancelled. It was decided that these interviews would be conducted over the telephone.

3.5.5 Differences between telephone and face-to-face interviews

Telephone interviewing differs from face-to-face interviews. According to Bryman (2004) there are advantages of telephone interviewing compared with face-to-face interviews. Firstly, they are cheaper and quicker to administer. Secondly, it has been suggested that interviewees' responses can be affected by the characteristics of the interviewer. This potential bias may not be present in telephone interviewing. However, there are disadvantages of telephone interviewing compared with face-to-face interviews. Firstly, generally the length of the interview is affected. A face-to-face interview is likely to last longer. Secondly, it has been suggested that there is greater difficulty asking questions around sensitive issues. Thirdly, there are issues around the observing of non-verbal communication such as interviewees' unease with a question or their understanding of a question. Lastly, it has been suggested that data derived from telephone interviews is subordinate compared to face-to-face interviews.

Within this study all four interviews with people with epilepsy were conducted face-to-face. Two out of the five interviews with professionals in the field of epilepsy were conducted over the telephone; the other three were face-to-face interviews.

The next section of this chapter outlines the research process. It provides details on the sample of participants, response rate, pilot questionnaire and data analysis.

3.6 Outline of the research process

As shown above, the methods within this research consisted of a focus group, a self-completion questionnaire and interviews. The focus group was completed to obtain information on quality of life issues from a sample of people with epilepsy. The information obtained from the focus group was used to aid the development of a self-completion questionnaire alongside a review of current literature in this area. Interviews with people with epilepsy themselves were conducted, to gain a more in-depth exploration of quality of life issues in epilepsy and also to support the statistical evidence obtained from the questionnaires. Interviews were also conducted with professionals working in the field of epilepsy.

The researcher also attended a number of conferences on an on-going basis over the 24 months. In the area of epilepsy Brainwave's Annual Conference was attended in September 2006 and the Neurological Association of Ireland (NAI) Conference as part of Brain Awareness week was attended in March 2008. In the area of research, the Postgraduate Annual Conference was attended in November 2007. Finally, the researcher presented this research by poster presentation at two conferences in May 2008, the Irish Neurological Meeting in Cork and the Sociological Association of Ireland Conference in Galway. The next sub-section discusses the sample of participants to the questionnaire.

3.6.1 Sample of participants to the questionnaire

The final questionnaire was distributed to 318 people living in the Western region of Ireland. The 318 people are members of Brainwave and therefore listed on their database. Membership of Brainwave is optional and therefore it is difficult to say how representative the sample is. However, the sampling techniques strove to reflect the members in terms of gender, age, and where they lived. This method of sampling was chosen as there is no official database regarding the number of people with epilepsy in Ireland.

A breakdown of the numbers of members in each of the nine counties was obtained from Brainwave. This enabled the researcher to code questionnaires and therefore establish which county completed questionnaires were returned from.

The purpose of this was to ascertain whether there were differences in quality of life issues depending on where the respondents lived. The following table illustrates the breakdown of numbers within each of these nine counties.

Table 4: Illustrates the breakdown of participants from each county

County	Total number on database	Number in sample	%
Donegal	35	16	45.71
Leitrim	4	3	75.00
Sligo	14	9	64.29
Roscommon	13	4	30.77
Mayo	36	14	38.89
Galway	61	21	34.43
Limerick	54	8	14.81
Clare	28	15	53.57
Tipperary	73	20	27.40
Total	**318**	**110**	

It is estimated that almost 40,000 people in Ireland have some form of epilepsy. The above table suggests that the majority of people with epilepsy are not members of Brainwave which is significant given that they are the only formal epilepsy organisation in Ireland. This highlights the need for a national database as to the number of people with epilepsy so that effective service provision can be planned for and provided.

Enclosed with each questionnaire was a cover letter which explained why the questionnaire was being posted to them, confidentiality was assured and the significance of their participation was stated (see Appendix E).

A stamped addressed envelope was included for convenience. The distribution of questionnaires took place in July and August 2007. The response rate is explained in the next sub-section.

3.6.2 Response Rate

Most studies draw a certain amount of non-response to questionnaires. In fact some authors suggest that there is a reduction in response rates within social research (Bryman, 2004). In an attempt to achieve a higher response rate from possible respondents and to follow up on those respondents who do not initially respond, a reminder letter was sent through Brainwave to each member, approximately 5 weeks after the questionnaire was distributed.

As previously stated the total number of questionnaires distributed was 318 of which 129 were returned. However, 19 of the 129 did not fit the criteria of adults (over 18) with epilepsy living in the western region of Ireland. Therefore, the total number deemed appropriate for analysis was 110 resulting in a response rate of 34.5%. Given the length and sensitive nature of the questionnaires and considering postal questionnaires usually result in low response rates (Bryman, 2004) the response rate of 34.5% could be deemed good. The sample of participants to the interviews is explained in the next sub-section.

3.6.3 Sample of participants to the interviews

The sampling technique used in conducting the interviews within this research was purposive sampling. This type of sampling is non-probability sampling. According to Bryman (2004:333)

> Such sampling is essentially strategic and entails an attempt to establish a good correspondence between research questions and sampling. In other words, the researcher samples on the basis of wanting to interview people who are relevant to the research questions.

Therefore, the researcher chose the participants for interviews who they thought were relevant to the research topic.

The researcher interviewed four people with epilepsy living in the Western region of Ireland to gain a more in-depth exploration of quality of life issues in epilepsy and also to support the statistical evidence obtained from the questionnaires.
Interviews were also conducted with key people in relevant organisations who provide services, offer support and information to people with epilepsy. The participants for interviews consisted of two community resource officers from Brainwave identifiable as CRO 1 and CRO 2, an epilepsy specialist nurse identifiable as ESN, an educator identifiable as ED and a Consultant Neurologist identifiable as CN. There were two main reasons for choosing these interviewees. Firstly, they were chosen because of their roles working with people with epilepsy and their experience working within the health care system. Secondly, due to their work, they have witnessed dramatic changes for people with epilepsy in recent years.

The researcher contacted the possible interviewees by phone/email to seek their co-operation. This method was used due to travel restrictions. The researcher introduced herself and explained the nature of the research being carried out. Their agreement was sought to participate in the research, via an interview. The researcher proceeded to arrange a date, time and place for the interview which was convenient to both parties. A guideline of interview questions was sent to each participant one week in advance of the interview taking place (see Appendix F). Interviews were tape recorded and transcribed by the researcher. Interviews were tape-recorded in conjunction with each of the interviewees' verbal consent. The pilot questionnaire is discussed in the next sub-section.

3.6.4 Pilot questionnaire

The questionnaire was piloted on a sample of people with epilepsy living in the Western region of Ireland. The pilot sample consisted of seven people with epilepsy. The pilot was done to evaluate the design of the questionnaire and to ensure questions were not misleading or hard to understand. Bell (1997:84) states

> The purpose of a pilot exercise is to get the bugs out of the instrument so that subjects in your main study will experience no difficulties in completing it and so that you can carry out a preliminary analysis to see whether the wording and format of questions will present any difficulties when the main data are analysed.

The pilot led to a number of changes being made to the questionnaire. The first change involved the wording of question 9. Originally, the question was; How long did you wait for an appointment?

It was apparent that the majority of the sample completing the pilot left this question blank, to ensure this question was answered in the final questionnaire the researcher added categories of time so that participants were given four options to choose from. The wording of 20(c) was changed, it was apparent that the wording of this question left the majority of participants confused as to what was actually being asked so the question was restructured to ensure coherency. A question on accidents at work was included (question 18). This issue had not being included in the pilot and the researcher felt a question on this issue was warranted. Five Likert scales were introduced at the end of each section. The Likert scales were developed through reviewing literature on the topic, and issues which were highlighted by participants of the focus group. The analysis of collected data will be further discussed in the next sub-section.

3.6.5 Quantitative data analysis

Sarantakos (2007:1) states

> Data analysis (DA) is the process of transforming raw data to numbers, applying statistical tools, and aiming to describe, summarise and compare data, and to discover knowledge.

Within this research the data consisted of information collected by the researcher in the form of completed questionnaires. The first step of analysis was coding. This means converting raw data into numbers, whereby each number represents a code and a code stands for a value or category (Sarantakos, 2007). For example, the possible answers to a question within the questionnaire consisted of yes, no and don't know; coding this meant that yes became 1, no became 2 and don't know became 3. The next step involves the defining of variables. A variable is a concept that has two or more values, gender is an example of a variable as it has two values; male/female. The defining of variables allows the computer program to automatically recognise, sort out and distribute the data (Sarantakos, 1988).

The statistical tool used for analysing the data collected from the questionnaires was SPSS (Statistical Package for the Social Sciences). This computer program was chosen as it offers a variety of features and is valid, reliable and efficient.

It is important to deal with missing answers within the questionnaire in order to analyse data accurately. Therefore, missing answers within this research were coded as 9 or 99. Given the length of the questionnaire a code book was developed (see Appendix D). This included details of how to assign numerical codes to the questions. The data obtained was then electronically coded onto an excel database by the researcher. An expert in this field was contacted and assisted with this stage in the research process. The data was cleaned, to ensure accuracy. Following this, the analysis of the data was completed. The data obtained was developed into graphs and tables. A number of cross-tabulations were also completed. Cross-tabulations are tables containing more than one variable and allows for a comparison of variables to be completed (see Appendix H). Information from the open-ended questions were categorised thematically and coded to enable the researcher to process the data and give a descriptive analysis of the findings. According to Sarantakos (1988:341)

> The analysis of the data allows the researcher to manipulate the information collected during the study in order to assess and evaluate the findings and arrive at some valid, reasonable and relevant conclusions

Qualitative data analysis is explained in the next sub-section.

3.6.6 Qualitative data analysis

The researcher transcribed each of the tape recorded interviews. The interviews were analysed through thematic analysis. The first step within this process involved thorough and repeated reading of the transcriptions. Holloway eds. (2005:153) states

> The process also involves constant comparison between words, sentences, paragraphs, codes and categories...the purpose is to identify similarities and differences in the data...with each interview compared...codes with similar meaning are linked together and renamed as categories to provide more abstract meaning.

The next step within the analysis of the data involves the connecting of categories and sub categories which allows a conceptual framework to develop. Themes that were apparent from this analysis are presented in the findings and discussion chapters.

Samples of excerpts from the interviews are included in the appendices (see Appendix I). The following section of this chapter discusses the ethical considerations of this research.

3.7 Ethical Considerations

Bulmer (1982) cited in Humphries (2000:70) states

> The scientific community has responsibilities not only to the ideals of the pursuit of objective truth and then search for knowledge, but also to the subjects of their research...the researcher has always to take account of the effects of his (sic) actions upon...subjects and act in such a way as to preserve their rights and integrity as human beings. Such behaviour is ethical research.

All participants within this research were adults, over the age of eighteen years and were aware that their participation was voluntary and refusal to participate was respected. In the context of the questionnaire, the sample of participants was selected through Brainwaves' member database, and therefore anonymous and voluntary, so consent was easier to obtain.

The focus group was voluntary and participants signed volunteer forms before the session commenced (see Appendix H). Permission of interviewees to be tape-recorded was sought before each interview commenced.

Confidentiality and anonymity were assured to all participants during the course of this research and this was honoured by the researcher. The researcher was objective as possible throughout this research in that all information and data obtained was given fair consideration. Moreover, findings were reported truthfully and with professional integrity. The following section discusses the strengths and limitations of this research.

3.8 Strengths and limitations of the research

The main strength of this research lay in the involvement of people with epilepsy in each stage of the research process. People with epilepsy are the people who know best how epilepsy impacts on an individual's life and therefore are essential in the development of a quality of life inventory/assessment. A further strength within this research was the use of triangulation.

As this involved in the use of multiple research methods it allowed the researcher to utilise the strength of each method to overcome the shortcomings of the other. Moreover, in using a focus group to aid the development of the questionnaire it allowed people with epilepsy to have input into the areas in which they felt should be explored during the course of the research. The questionnaire then allowed this information to be obtained focusing specifically on people with epilepsy living in the Western region of Ireland. The interviews took into account the opinions, attitudes and feelings of professionals working in the field of epilepsy but also allowed people with epilepsy themselves to 'voice' their attitudes, feelings, opinions and experiences of living with the condition. In addition, the interviews with people with epilepsy were completed to support the statistical evidence obtained from the questionnaires.

The main limitation within this research was the difficulty accessing participants in relation to both the focus group and the self-completion questionnaire. To date there is no official database as to the number of people with epilepsy in Ireland, which led to difficulties in accessing people with epilepsy. Therefore, the researcher contacted Brainwave to seek their participation and questionnaires were distributed to their members, which consisted of 318 people. However, not every member has epilepsy and there is no way of knowing how many people with epilepsy are actually members of Brainwave. Therefore, the researcher has no way of knowing how representative the sample within this research is which leaves it difficult to generalise the findings of the research. However, the sampling technique used strove to reflect the members on the Brainwave database as it incorporated people from different counties, of different ages and gender. Another limitation related to the focus group: if completing this research again, more than one focus group would be advantageous in providing a more in-depth exploration of the experiences and issues relating to quality of life for people with epilepsy.

Another limitation which became apparent during the course of the research involved the questionnaire. Although the questionnaire was piloted, an issue arose during the analysis. Participants were asked their age by ticking a category (20-29yrs/30-39yrs etc) and they were also asked to specify in years how long they have epilepsy, this led to a difficulty in establishing exact age of onset of epilepsy.

Therefore, a question on this should have been included. If conducting further research in this area age of onset of epilepsy is an important factor to consider in exploring quality of life issues for people with epilepsy.

3.9 Conclusion

This chapter provides information on the research methods used in order to explore quality of life issues for people with epilepsy living within the Western region of Ireland. The main aim of this chapter was to justify and explain the methodology used to carry out this research. This was achieved through triangulation, the use of both quantitative and qualitative methods in the collection and analysis of data.

Further, a broad ranging literature review was completed which provided an overview of quality of life assessment. Quality of life and physical, social and psychological impacts for people with epilepsy were discussed. Moreover, universal quality of life impacts for people with epilepsy were also explored. The presentation of the findings and discussion achieved by using the chosen research methods will be provided in detail in the next chapter.

4.0 Findings and Discussion

4.1 Introduction

To determine and explore issues which affect the quality of life of people with epilepsy living in the Western region of Ireland, the researcher devised a self-completion questionnaire which was distributed to respondents who are members of Brainwave, the Irish Epilepsy Association. The total number of questionnaires distributed was 318 with 129 being returned. However, 110 questionnaires were deemed appropriate for analysis resulting in a response rate of 37%. The questionnaire was divided into four categories; general questions, physical impacts, social impacts and psychological impacts. Each questionnaire was given an identification number (IDNO) before analysis began. Therefore, when the researcher is quoting a response from a questionnaire it will be denoted by the IDNO. One focus group with people with epilepsy was also completed. This was done to aid the development of the questionnaire and participants will be denoted by F1, F2, F3 and F4.

Interviews were also conducted within this research, and consisted of nine interviews; five with professionals working in the field of epilepsy and four people with epilepsy were interviewed. Questions within these interviews were grouped similarly to that of the questionnaire using the same four categories. In order to protect the identity and assure confidentiality of the interview participant's identifiable words such as names, places etc will be omitted from quotations. Persons with epilepsy are denoted by P1, P2, P3 and P4. Professionals in the field of epilepsy are denoted by their titles, the Consultant Neurologist is CN, the community resource officers are CRO 1 and CRO 2, the educator of people with epilepsy is ED and the epilepsy specialist nurse is ESN.

In order to present findings from the data collected using all research methods it was decided that this would be best achieved by using four separate findings and discussion chapters. The first chapter will present the findings in relation to quality of life and physical impacts for people with epilepsy. It will also give a general background of respondents and interview participants. The second chapter will present the findings and discussion in relation to quality of life and social impacts for people with epilepsy.

The third chapter will present the findings and discussion in relation to quality of life and psychological impacts for people with epilepsy. The fourth chapter will present the findings and discussion of universal quality of life impacts for people with epilepsy. Each chapter will incorporate findings from all methods used namely, the focus group, questionnaires and the interviews.

This research was guided by a number of hypotheses that emerged through a review of the literature. Firstly, quality of life issues are under-researched in Ireland. Secondly, there are real physical, social and psychological impacts for people living with epilepsy. Thirdly, epilepsy impacts on the quality of life of those living with the condition. Overall these impacts appear to be negative but may be subject to the context of the individual. Each of these hypotheses will be explored in the discussion section of each of the four chapters.

4.2 Quality of life and physical impacts for people with epilepsy: Findings and discussion

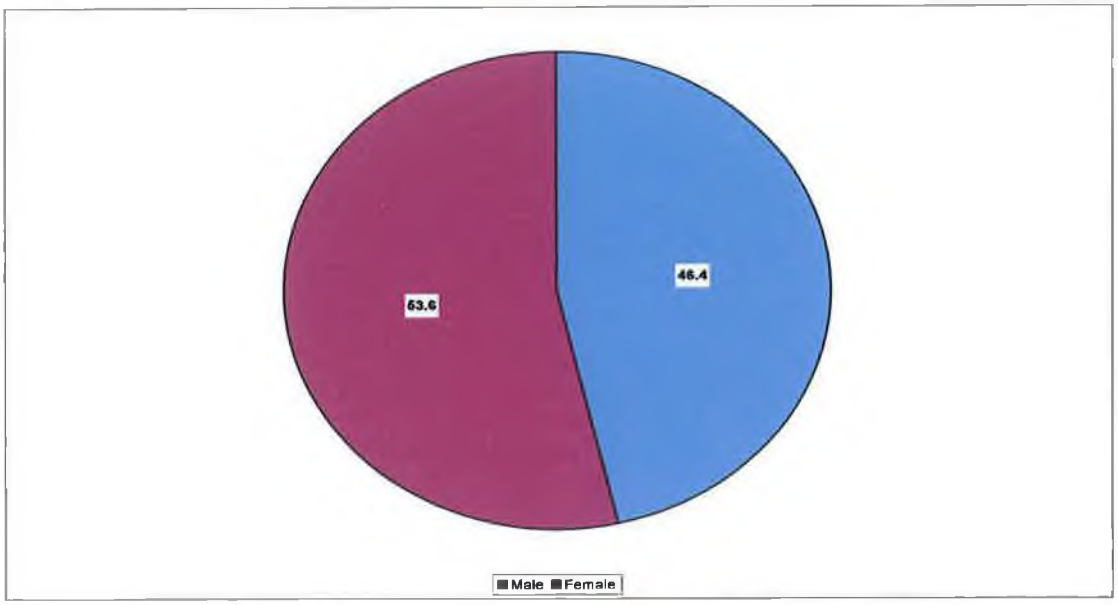
4.2.1 Introduction

This chapter will present the findings and discussion of this research and is divided into three sections. The first section will provide details in relation to the general background of respondents such as gender, age, and marital status. The second section will provide details of quality of life and physical impacts for people with epilepsy living in the Western region of Ireland. These impacts include medication, seizure frequency, alcohol, sleep and seizure frequency, physical fitness and accidents. Finally, the third section endeavours to discuss the findings of this research and how these relate to previous research carried out in the area. This section will also explore the guiding hypotheses of the research.

4.2.2 General background of respondents

Of the 110 respondents to the questionnaire 46% (n=51) were male and 54% (n=59) were female.

Figure 2: Illustrates gender of respondents to the questionnaire.

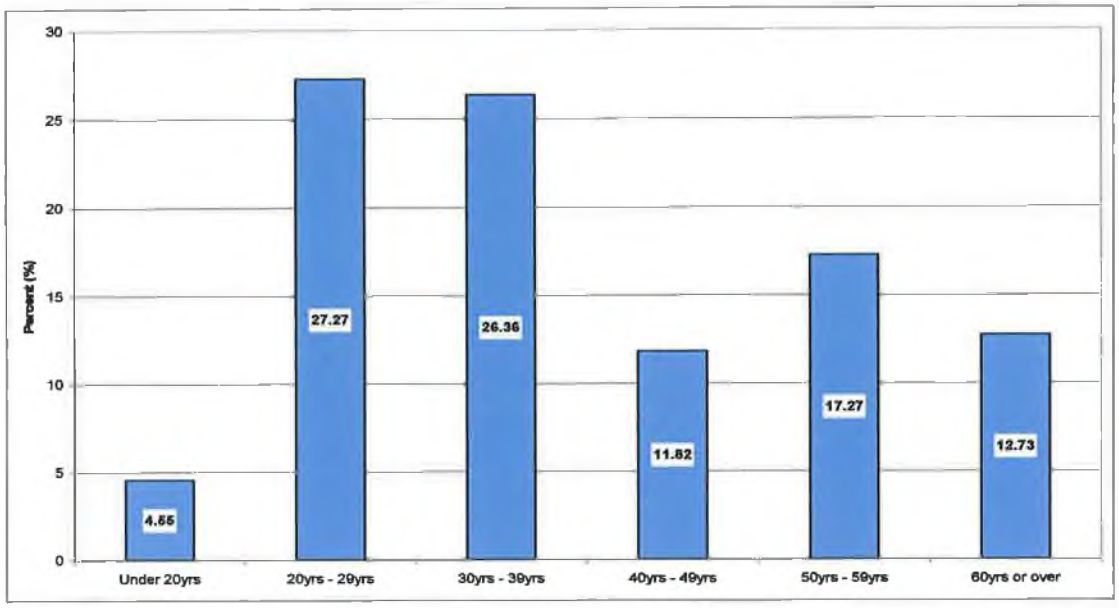


Of the 110 respondents to the questionnaire, 23% (n=25) reported a history of epilepsy in their family. Aunts, uncles, cousins, grandparents, brother, sisters, sons, fathers and mothers were mentioned as having epilepsy. The following table provides details on the general backgrounds of the four interview participants.

Table 5: Illustrates the general background of interviewees

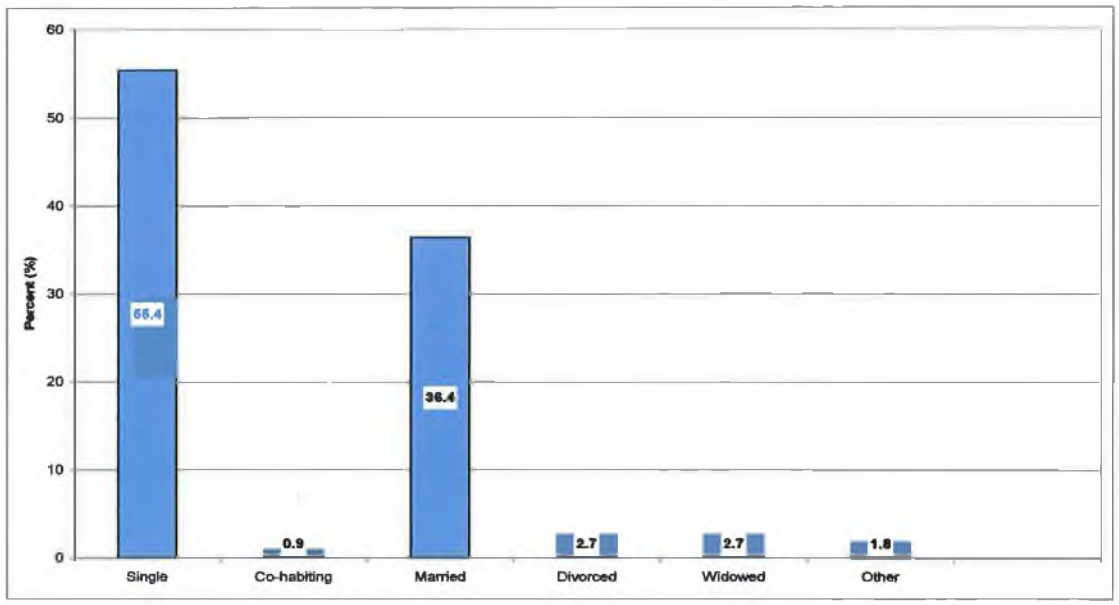
Interviewee	Gender	Age	Marital Status	Age of onset of epilepsy	History of epilepsy
P1	Female	36	Single	4	Brother
P2	Female	22	Single	19	Cousin
P3	Female	48	Married	10	No history
P4	Male	24	Single	15	No history

Figure 3: Illustrates age of respondents by categories stated in the questionnaire.



The above figure illustrates that the highest responses were from the 20-29 yr age group (27%, n=30) and 30-39% age group (26%, n=29) while only 13% (n=14) were in the 60 yrs and over age group.

Figure 4: Illustrates the marital status of respondents.



This figure illustrates that over half of respondents to the questionnaire were single. This may be due to the majority of respondents being in the younger age categories.

The length of time respondents has epilepsy ranged between one and 60 years. The following table illustrates the average length of epilepsy according to the age groups of the respondents.

Table 6: Illustrates average duration of epilepsy in each age group

Age	N	Mean
Under 20	5	4.80
20-29 years	28	14.50
30-39 years	29	18.14
40-49 years	13	22.46
50-59 years	19	18.74
60yrs or over	13	22.08

The mean is the average duration of epilepsy. The above table illustrates that people in the older age groups have had epilepsy longer. The table also suggests that respondents in the under 20 years and 20-29 year age groups were children and young teenagers when they were diagnosed with epilepsy.

4.2.3 Medication

99% (n=109) of the respondents are currently taking anti-epileptic medication. The following table provides details as to the number of anti-epileptic medications respondents currently take.

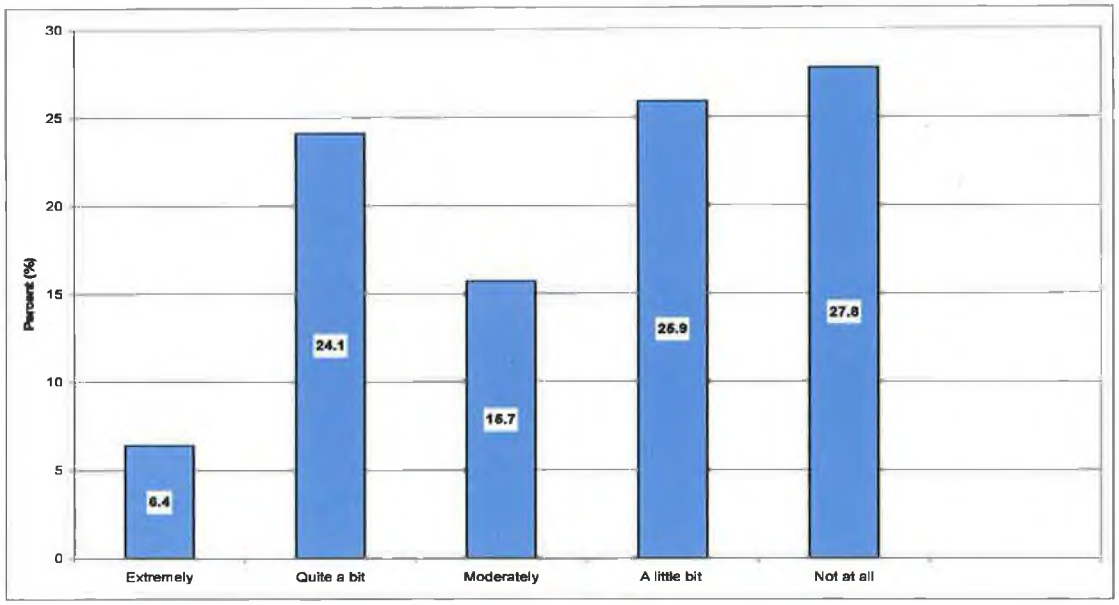
Table 7: Illustrates the number of anti-epileptic medication taken by respondents

	N	%
One	51	47
Two	23	21
Three or more	35	32
Missing	1	
Total	**110**	

This table illustrates that almost half of respondents only take one type of medication for their epilepsy. However, almost one-third of respondents take three or more types of medication.

When asked if taking medication affected their quality of life respondents reported; 'extremely' in 6% (n=7), 'quite a bit' in 24% (n=26), 'moderately' in 16% (n=17) 'a little bit' in 26% (n=28) and 'not at all' in 28% (n=30) of cases. This is illustrated in the following figure.

Figure 5: Illustrates how much taking mediation affects respondent's quality of life



This figure illustrates that almost half of respondents feel taking medication affects their quality of life. This suggests a link between medication and quality of life for people with epilepsy.

When respondents were asked to state their level of agreement with the statement; *'Taking anti-epileptic medication interferes with my quality of life'*, 26% (n=26) strongly agreed, 26% (n=26) agreed, 8% (n=8) were undecided, 28% (n=28) disagreed and 11% (n=11) strongly disagreed with this statement. The following table illustrates these results.

Table 8: Respondents level of agreement with the statement 'Taking anti-epileptic medication interferes with my quality of life'

	N	%
Strongly Agree	26	26
Agree	26	26
Undecided	8	8
Disagree	28	28
Strongly Disagree	11	11
Missing	2	
Total	**110**	

Although, only 24% of respondents reported medication affects their quality of life 'quite a bit' (fig.5) when asked if medication interferes with quality of life 52% either strongly agreed or agreed that it did. This suggests that some respondents feel medication does not affect their quality of life but it does however interfere with it.

With regard to interview participants medication was an issue for them but in very different ways. For instance, P2 got very bad migraines, was sent for scans to the hospital and saw a consultant who put her on medication for her migraines. As she explains

> '…I'd say I wasn't on them two weeks and then all of a sudden this other stuff happened and then about two months later I was diagnosed with epilepsy but I think myself anyway that it was those tablets that triggered it off' (P2).

She takes anti-epileptic medication and finds

> 'The tablets help my migraine…I might get two headaches a week…but nothing compared to what I used to have but the tablets I'm on make me tired and lack concentration so what I do is, I take them for maybe a week and then I'll leave them for a while and then if my headaches are getting worse I go on them for another week or two just to keep the level up' (P2).

Another interviewee elucidates the trigger of her epilepsy, as she states

> 'When I was expecting the two of my children…for the two pregnancies I never, ever took one fit…and it was after that then that I really thought that the epilepsy was connected to my menstrual cycle…when I started to monitor myself then and it was either coming before it or after it' (P3).

P4 was prescribed medication initially but was taken off it when he was re-diagnosed a number of years later as medication would not help his type of epilepsy. As he explains

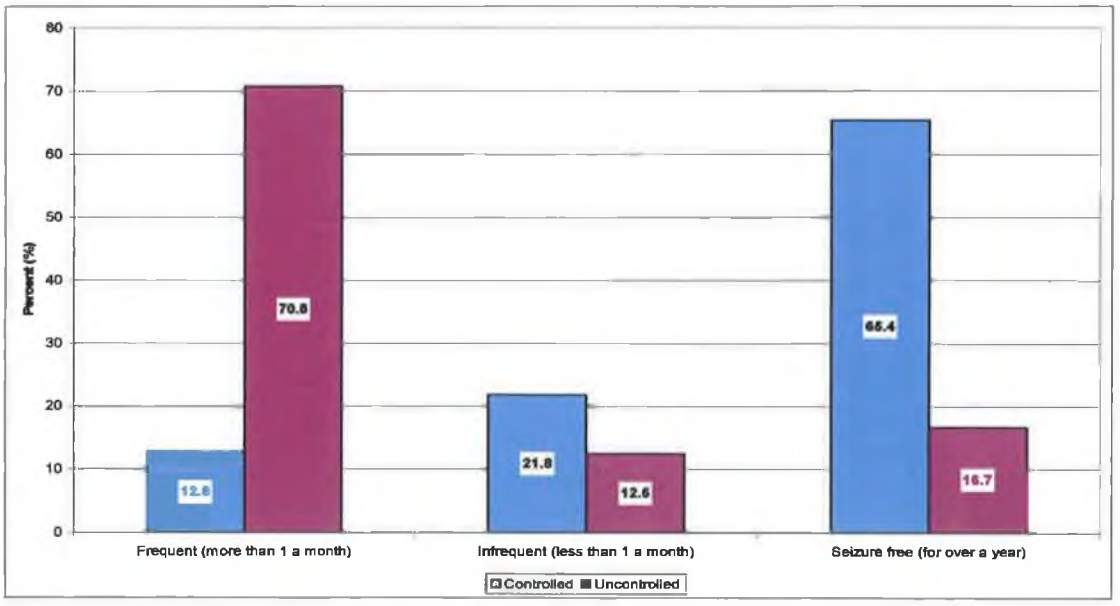
> '...what happened is I had a bullying incident in school basically and as a result of what happened I developed a form of epilepsy...called pseudo epilepsy which the best way to describe it is that its psychologically based' (P4).

These comments suggest that the majority of interview participants had pin-pointed the 'cause' or trigger of their seizures. The first interviewee felt that migraine medication had triggered her epilepsy. The second had linked her epilepsy with her menstrual cycle and the last interviewee had developed a form of epilepsy due to a bullying incident at school.

4.2.4 Seizure frequency

Seizures were controlled in 77% (n=79) of respondents and uncontrolled in 23% (n=24) of respondents. The following figure illustrates the frequency of respondents seizures within two categories, namely controlled and uncontrolled.

Figure 6: Illustrates the frequency of respondent's seizures within two categories; controlled and uncontrolled.



The above figure illustrates that within the uncontrolled category 71% (n=17) of respondents reported their seizures as frequent more than one a month and 17% (n=4) reported being seizure free for over a year.

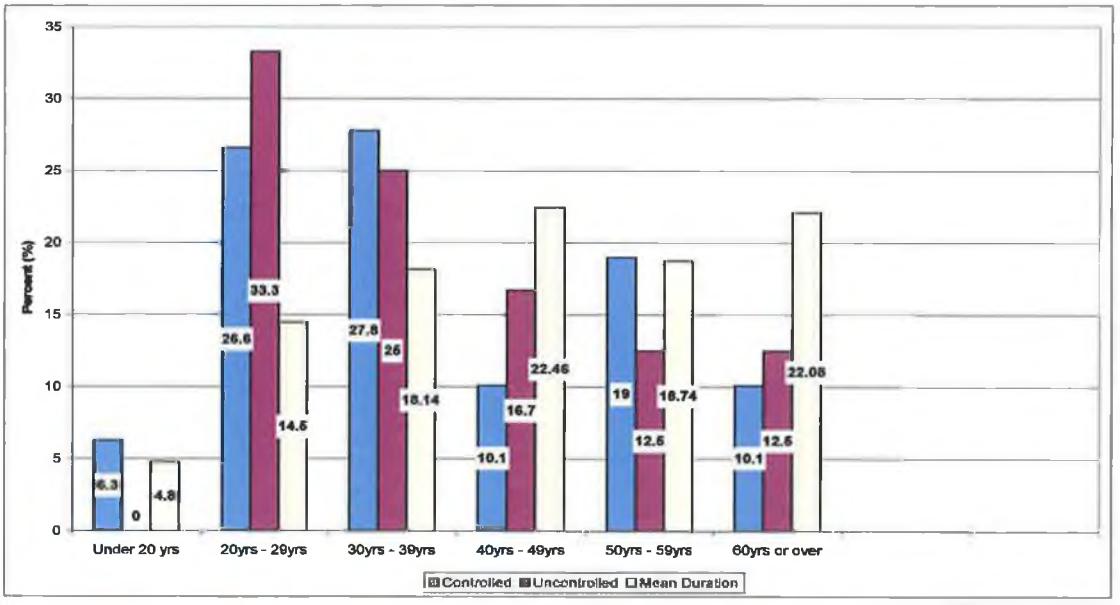
Within the controlled category 13% (n=10) of respondents reported their seizures as frequent more than one a month and 65% (n=51) reported being seizure free for over a year. It is interesting that in the controlled category 13% of respondents have frequent seizures and in the uncontrolled category 17% of respondents are seizure free. This suggests there may be a need to clearly define controlled and uncontrolled epilepsy.

Table 9: Illustrates the breakdown of seizures compared with gender of respondents

	Controlled Seizures	Uncontrolled Seizures
Male	48	50
Female	52	50

This table illustrates there was little difference between gender in relation to whether seizures were controlled or uncontrolled. The following figure illustrates the breakdown of seizures compared with age of respondents and mean duration of epilepsy.

Figure 7: Illustrates the breakdown of seizures compared with age of respondents and mean duration of epilepsy



The above figure illustrates that duration of epilepsy seems to have little effect on whether seizures are controlled or uncontrolled in the different age categories.

Respondents were asked to state their level of agreement with the statement *'Seizure frequency has a negative impact on my quality if life'* 28% (n=27) strongly agreed, 34% (n=33) agreed, 11% (n=11) were undecided, 18% (n=18) disagreed and 9% (n=9) strongly disagreed with this statement. The following table illustrates respondent's level of agreement with this statement.

Table 10: Respondents level of agreement with the statement 'Seizure frequency has a negative impact on my quality of life'

	N	%
Strongly Agree	27	28
Agree	33	34
Undecided	11	11
Disagree	18	18
Strongly Disagree	9	9
Missing	12	
Total	**110**	

This table suggests that the majority of respondents either strongly agree or agree that seizure frequency has a negative impact on their quality of life. In addition, question 13 in the questionnaire asked respondents to describe how seizure frequency affects their quality of life. The following are some responses

> 'Very difficult to cope with the uncertain nature of the problem, very nervous about being out and about' (IDNO: 15).
>
> 'I never go out on my own as I've lost confidence in myself. I mean go out as in, go for a walk, go shopping, cross a busy street' (IDNO: 19).
>
> 'Now, it's more of a worry that they'll return (18 months since last one) I'm wary travelling (access to meds). Only recently started driving again and worry constantly about that. Don't believe I was ever diagnosed properly – Don't know the cause and prognosis' (IDNO: 34).
>
> 'I am at home and put the kids out to school and receive them so when this isn't possible my day is spent in bed and my wife will have to delay her day and come home early from work, as I sleep off the effects of a seizure' (IDNO: 66).

In contrast other responses included

'The seizures are under control now so the effect is minimal' (IDNO: 46)

'The seizures don't affect my quality of life' (IDNO: 80)

'My quality of life is good' (IDNO: 100)

The majority of respondents had negative comments with regard to how seizure frequency affects their quality of life. Driving restrictions, lack of confidence, dependence on others and the effects on other family members were mentioned. This suggests that seizure frequency has a negative impact on quality of life of people with epilepsy.

4.2.5 Alcohol, sleep and seizure frequency

Of the 110 respondents, 49% (n=54) drink alcohol. However, 35% (n=26) reported alcohol has an effect on their seizure frequency. The following table illustrates the distillation of responses from the questionnaire with regard to the effects alcohol has on respondent's seizure frequency.

Table 11: Illustrates effects of alcohol on seizure frequency

Effects of alcohol	N	%
Combination of alcohol and lack of sleep cause seizures	6	19
Seizure threshold affected by alcohol intake	10	32
Alcohol consumed with great caution	15	48
Missing	79	
Total	**110**	

The above table suggests that due to the effect alcohol has on seizure frequency the majority of respondents consume alcohol with great caution 48% (n=15).

Lack of sleep having an effect on seizure frequency was reported by 68% (n=70) of respondents, 20% (n=21) felt that it had no effect. The following table illustrates the distillation of responses from the questionnaire with regard to ways in which respondents feel lack of sleep has an effect on respondent's seizure frequency.

Table 12: Illustrates effects lack of sleep on seizure frequency

Effect of lack of sleep	N	%
Inadequate sleep has an affect on my seizure frequency	48	84
Medication causes tiredness	2	4
Have problems sleeping	3	5
Not sure	4	7
Missing	53	
Total	**110**	

The above table illustrates that the majority of respondents agree that lack of sleep affects their seizure frequency. However, only 5% (n=3) of respondents reported having problems sleeping.

4.2.6 Physical fitness

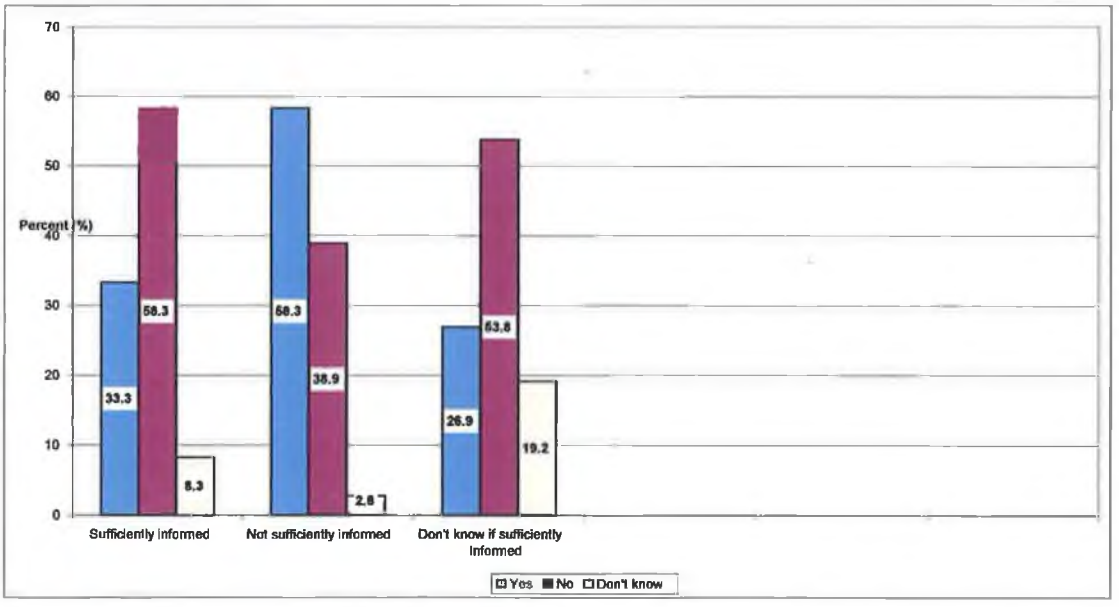
Respondents participate in sport/leisure activities regularly in 42% (n=46) of cases, while 43% (n=46) feel that their epilepsy has an impact on their sport/leisure activities. The following table illustrates reasons respondents do not participate in sport/leisure activities.

Table 13: Illustrates reasons for not participating in sport/leisure activities

Reasons for not participating	N	%
Time limits	11	15
Epilepsy Itself	14	19
Fear of seizure	15	21
Lack of motivation	15	21
Advised not to	6	8
Other	12	16
Missing	37	
Total	**110**	

From this table it can be said that 40% (n=29) of respondents do not participate in sport/leisure activities as a direct consequence of their epilepsy or fear of seizure, with 8% (n=6) reporting they were advised not to participate. In addition, other reasons respondents gave for not participating included; need for supervision, old age, lack of transport and medication causes extreme tiredness. Respondents had experienced a seizure during sport/leisure activities in 26% (n=27) of cases. Moreover, 37% (n=37) of respondents felt that they had not been sufficiently informed relating to participating in sport/leisure activities.

Figure 8: Illustrates whether respondents feel sufficiently informed in relation to sport/leisure activities compared with whether they felt their epilepsy impacts on sport/leisure activities



This figure illustrates respondents who feel their epilepsy effects their sport/leisure activities do not feel sufficiently informed in relation to sport/leisure activities. This suggests that if respondents were adequately informed about sport/leisure activities they may be less likely to feel their epilepsy affects their sport/leisure activities. In this area the CN said

> '...generally we would encourage people to live a normal life as possible. We wouldn't tell people to stop playing sports...there are people with epilepsy playing games so we would just tell them to be sensible about it'

One interviewee stated

> 'Mammy recommended not to, like I used to go cycling when I was young but then mam said ..... no because when I get dizzy now you know get a warning she says no .... that's not good you know so I have a bike and its lying in the shed and I've only been on it three times its just lying there you know things like that' (P1)

However, P3 said

> '...I've never let it rule my life; I have always done the ruling with it. You know if people say to me you can't go swimming, I go swimming. If someone says you can't ride a bike, I'd ride a bike. I've always done the opposite to what I've been told; always since I was ten years old I never, ever let epilepsy affect my life'

The Consultant Neurologist said that they would recommend people with epilepsy to live as normal a life as possible but to be sensible in relation to sport/leisure activities. In contrast one interview participant said whatever she was told not to do; she did it anyway, while another interview participant said her mother had advised her not to participate in some sport/ leisure activities. This suggests that there may be a number of factors which affects whether respondents participate in sport/leisure activities. Firstly, it may depend on the amount of information received relating to participation. Secondly, participation in sport/leisure activities may be dependent on the respondents own choice and thirdly, overprotection may be a factor.

4.2.7 Accidents

In the questionnaire, 58% (n=63) of respondents worry about injuring themselves when they have a seizure. The following table illustrates injuries respondents received as a result of a seizure in the last year.

Table 14: Illustrates injuries respondents reported in the last year as a result of seizure

Injury	N	%
Burn/scald	13	12
Head injury	24	22
Cuts/bruises	36	33
Back pain	14	13

Forty-three percent (n=47) of respondents reported no injuries in the past year. In addition, respondents were asked if they had ever been injured as a result of a seizure with 54% (n=47) having being injured. This suggests that injuries resulting from seizures are common for people with epilepsy. The most common being cuts and bruises.

4.2.8 General Health

The respondents were asked two questions in relation to their health; question 14 asked respondents to rate their general health whereby 8.3% (n=9) rated it 'excellent', 30.3% (n=33) rated it as 'very good', and 21.1% (n=23) rated it as 'fair'.

The second question was a Likert scale which asked respondents to state their level of agreement with the statement *'My general health is excellent'* whereby 40.6% (n=41) of respondents agreed with this statement (see figure 8).

Table 15: Respondents level of agreement to the statement 'My general health is excellent'

	N	%
Strongly Agree	12	12
Agree	41	41
Undecided	13	13
Disagree	23	23
Strongly Disagree	12	12
Missing	9	
Total	**110**	

Of those who agreed with the statement 41.9% (n=31) have controlled seizures and 36.4% (n=8) have uncontrolled seizures. This suggests that in this study respondents with controlled seizures were more likely to report their general health as excellent.

4.3.7 Quality of life and health

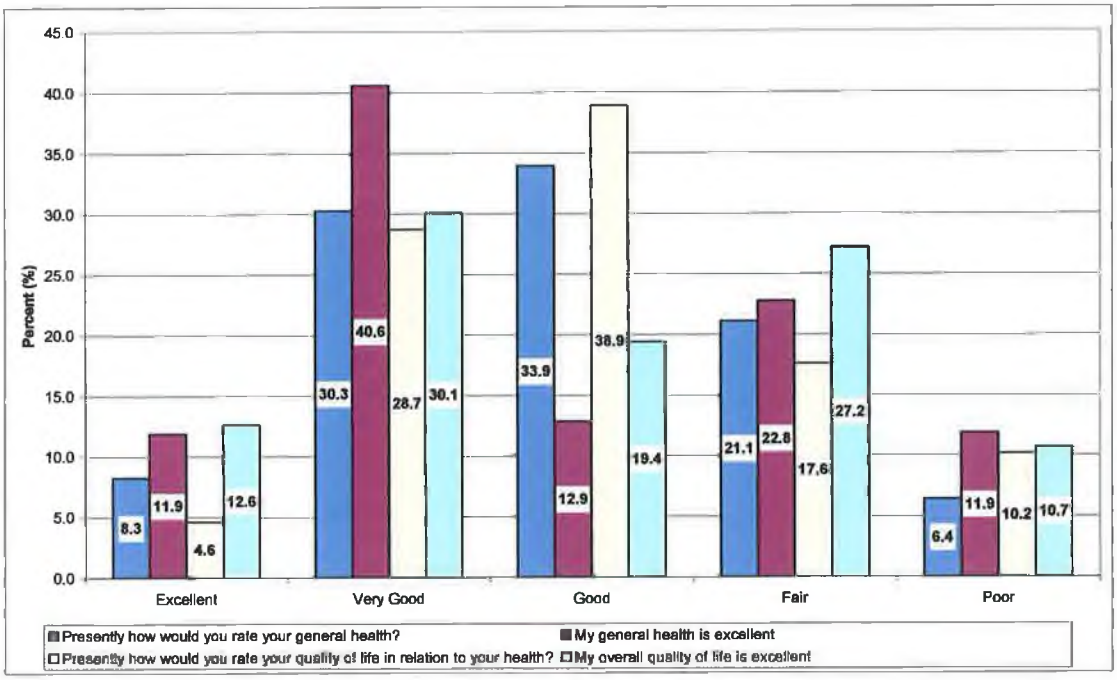
Respondents were asked two questions in relation to quality of life; question 15 asked respondents to rate their quality of life in relation to their health whereby 4.6% (n=5) rated it as 'excellent', 28.7% (n=31) rated it as 'very good' and 17.6% (n=19) rated it as 'fair'. The second question was a Likert scale which asked respondents to state their level of agreement with the statement 'My overall quality of life is excellent' whereby 30.1% (n=31) of respondents agreed with this statement (see figure 8).

Table 16: Respondents level of agreement with the statement 'My overall quality of life is excellent'

	N	%
Strongly Agree	13	13
Agree	31	30
Undecided	20	19
Disagree	28	27
Strongly Disagree	11	10
Missing	7	
Total	**110**	

Of those who agreed with the statement 31.1% (n=23) have controlled seizures and 26.1% (n=6) have uncontrolled seizures. Therefore, within this study respondents with controlled seizures were more likely to report their overall quality of life as excellent.

Figure 9: Illustrates how respondents rate their general health and their quality of life in relation to their health



4.2.10 Conclusion

This chapter highlights a number of issues on quality of life and physical impacts for people with epilepsy living in the Western region of Ireland. The findings suggest that almost half of respondents feel taking medication affects their quality of life. Moreover, some respondents felt that medication does not affect their quality of life but it does however interfere with it. The majority of respondents describe their seizures as controlled and there was little difference between seizure frequency and gender. This study suggests that seizure frequency has a negative impact on quality of life of people with epilepsy. It was apparent that 40% of respondents do not participate in sport/leisure activities as a direct consequence of their epilepsy or fear of seizure. In addition, over half of respondents rated their general health as excellent or very good. Respondents' quality of life in relation to their health was rated slightly lower. These issues are discussed in more detail in the discussion section of this chapter.

4.3 Discussion

It is apparent from the findings of this chapter that the guiding hypotheses of this research are confirmed. Firstly, quality of life issues for people with epilepsy are under-researched in Ireland. This was evident in the apparent lack of Irish studies relating to quality of life in which to correlate the findings of this research. Secondly, there are real physical impacts for people living with epilepsy and thirdly, epilepsy impacts on the quality of life of those living with the condition. The confirmation of the two latter hypotheses is revealed in the following discussion.

Some authors suggest that there is a higher incidence of epilepsy in males (Sander, 2005). This was not found within this study as there were almost an equal number of both male and female respondents to the questionnaire. This could be due to the sampling technique and the difficulty of not knowing how representative the sample employed within this study was. It was expected that the most responses would be from younger and older age groups with the literature stating that these were the two most common times to develop epilepsy (Sander, 2005). However, most responses in this study were received from the 20-29 year and 30-39 year age groups. When a comparison of age and length of years respondents have epilepsy was made it showed that the mean duration of epilepsy for the 20-29 year age group was 14.50 and for the 30-39 year age group was 18.14. However, a limitation highlighted previously in the methodology chapter was in relation to the lack of a specific question on age of onset of epilepsy. This may have given a clearer picture in relation to this issue. Nonetheless, this suggests that the majority of respondents to the questionnaire and interview participants were children or young teenagers when they were diagnosed with epilepsy. The literature suggests that people with epilepsy are less likely to be married (Callaghan et al, 1992). Over half of respondents to the questionnaire and the majority of interviewees were single. Although, this may have been due to the majority of respondents being in the younger age categories or the sampling technique used within this study as previously outlined.

The findings of this study highlight a number of factors with regard to seizure frequency. Firstly, it was expected that respondents who described their seizures as controlled would not have frequent seizures but would be seizure free.

However, in this study 77% of respondents reported their seizures as controlled, of those 65% were seizure free and 13% had frequent seizures. This implies that there is some confusion in how people with epilepsy describe their seizures and suggests the need for controlled and uncontrolled epilepsy to be clearly defined. Secondly, there was little difference between the controlled and uncontrolled categories in relation to gender. Thirdly, 62% of respondents either strongly agreed or agreed that seizure frequency has a negative impact on their quality of life. This was surprising considering 82% of respondents were seizure free and supports Fisher et al (2000) who suggests that the unpredictability of epilepsy is a key factor in how people perceive their quality of life. In addition, Harden et al (2007) found the physical facets of seizure severity can impact on the day-to-day activities of people with epilepsy.

According to Brainwave, the Irish Epilepsy Association people with epilepsy may need to take more care when consuming alcohol than that of the general population. The findings of this study support this as 32% of respondents felt that alcohol affected their seizure frequency. However, almost half of respondents (48%) reported that they consume alcohol with great caution. Moreover, the findings indicate that 84% of respondents felt that inadequate sleep affects their seizure frequency. However, only 5% reported having problems sleeping which supports Malow (2007) who suggests that sleep and epilepsy are interrelated. Moreover, deWeerd et al (2004) found that sleep disturbance is twice as prevalent in patients with epilepsy and quality of life was significantly and independently impaired in those with epilepsy. This suggests the need for closer examination of the relationship between sleep and epilepsy and ultimately how this may affect quality of life.

Within this study 43% of respondents felt their epilepsy impacts on their sport/leisure activities. Forty percent of respondents do not participate in sport/leisure activities as a direct consequence of their epilepsy or fear of seizure. Steinhoff et al (1996) found that people with epilepsy were less active than the general population. The main reason for this was the lack of information from health professionals with less than half of respondents reporting being sufficiently informed. The findings of this research support Steinhoff et al (1996) as only 37% of respondents felt they were sufficiently informed in relation to performing sports.

Moreover, of those who reported their epilepsy impacts their sport/leisure activities, 58% felt that they were not sufficiently informed. This suggests that people with epilepsy may require additional information and support in this area.

Cornaggia et al (2006) suggests that people with epilepsy are at a higher risk of accidents at work than that of the general population. Within this study 20% of respondents have had an accident at work due to experiencing a seizure. This supports Beghi et al (2002) who found that 24% of accidents at work were seizure related. Moreover, in this study 58% of respondents worry about injuring themselves when they have a seizure. This may suggest that it may not necessarily be accidents at work as a result of a seizure rather the worry about injuring themselves that impacts on quality of life for people with epilepsy. However, this link warrants further exploration.

5.0 Quality of life and social impacts for people with epilepsy: Findings and discussion

5.1 Introduction

This chapter is divided into two sections. The first section will present the findings of this research in relation to quality of life and social impacts for people with epilepsy living in the Western region of Ireland. Details are provided in relation to social activities, education, employment, driving restrictions, stigma and epilepsy myths. The second section provides a discussion of the findings of this research and how they relate back to previous literature in the area. The guiding hypotheses of this research will also be explored in this section.

5.1.1 Social Activities

Respondents reported their epilepsy has an impact on their social activities (such as visiting friends and family) in 51% (n=54) of cases. Respondents were asked to state their level of agreement with this statement *'My epilepsy interferes with my social activities'*, they reported as follows; 27% (n=27) strongly agreed, 33% (n=33) agreed, 10% (n=10) were undecided, 24% (n=24) disagreed and 6% (n=6) strongly disagreed with this statement. This is illustrated in the following table.

Table 17: Respondents level of agreement with the statement 'My epilepsy interferes with my social activities'

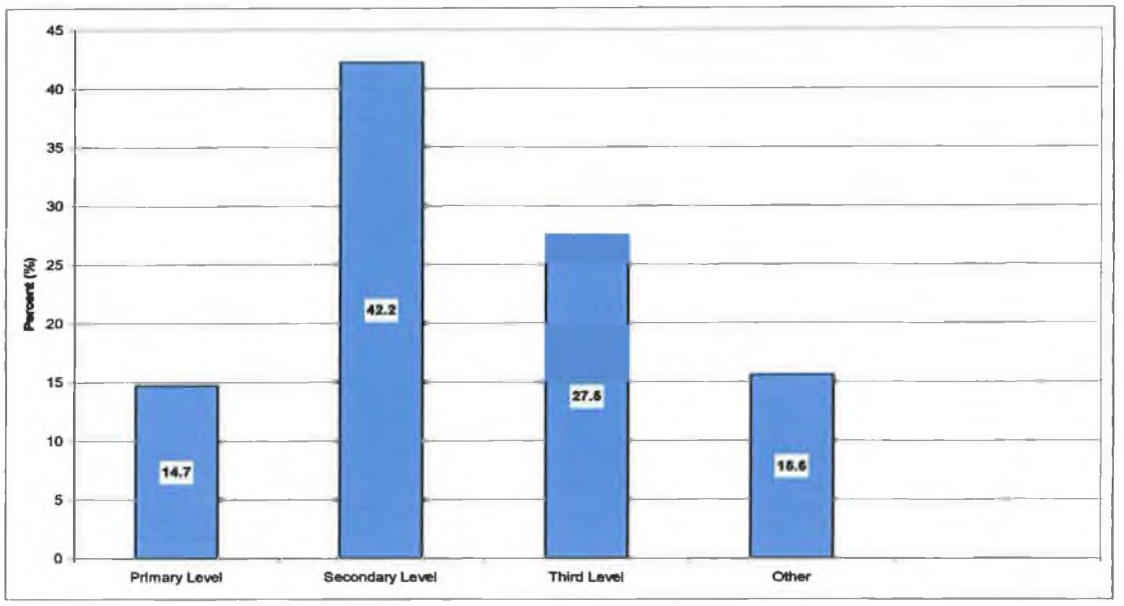
	N	%
Strongly Agree	27	27
Agree	33	33
Undecided	10	10
Disagree	24	24
Strongly Disagree	6	6
Missing	10	
Total	**110**	

This table illustrates that over half of respondents in this study reported their epilepsy interferes with their social activities.

5.1.2 Education

Within this study 42% (n=46) of respondents have completed secondary level education and 28% (n=30) completed third level education. This is illustrated in the following figure.

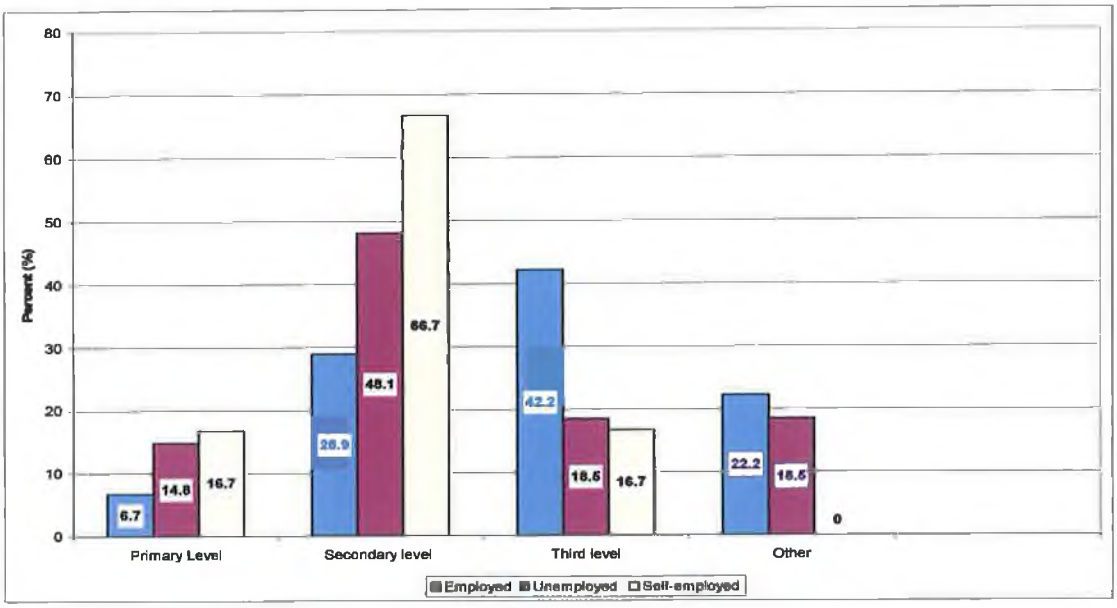
Figure 10: Illustrates educational achievement of respondents



5.1.3 Employment

The current employment status of respondent's was; 42.1% (n=45) were employed; 25.2% (n=27) were unemployed; 5.6% (n=6) were self-employed; 9.3% (n=10) were retired; 9.3% (n=10) were homemakers and 8.4% (n=9) were students. The following figure illustrates the current employment status of respondents compared with their educational attainment.

Figure 11: Illustrates current employment status of respondent's compared with level of education



The above table illustrates that respondents who were employed or self-employed were more likely to have achieved third level education. This suggests that the level of educational attainment of respondents may be linked to future employment status.

Employment status was compared with whether respondent's seizures were controlled or uncontrolled and found that of those who were currently employed 64% (n=35) and self-employed 9% (n=5) described their seizures as controlled. Of those who were currently unemployed 27% (n=15) described their seizures as controlled. This suggests that the majority of respondents who were employed and self-employed described their seizures as controlled whereas almost one third of those unemployed described their seizures as controlled. This suggests that respondents with controlled epilepsy are more likely to be in employment. However, this issue is explored further in the discussion section of this chapter.

Within the interviews; P1 and P2 were employed, P2 and P4 were both currently in third level education. When asked about whether they feel their epilepsy affects their employment prospects P1 responded

> 'Well when I started first working in my teens I applied for a job I was turned down, you know they were chatting away to me in the interview but when I told them I had epilepsy that was it, that hurt me big time because when you go in for a job you think this is great…once I told them I had epilepsy, no it was no good'

Further, another interviewee stated

> 'Sometimes I can get kind of conscious and don't say it and then after it has gone so long, what if I say it now? So in situations like that I just keep quiet, there would be one or two people that I work with that would know' (P4)

In the area of disclosure participant two in the focus group said

> 'It's never popped into my head as such, they'd never really ask the question anyway. They believe that I'm the same as everybody else. I don't bother unless they ask me, you know, medically is there anything wrong and I'd tell them then and there's no bother afterwards they never say a word, treat me as all the rest of them' (F2)

When employed 22% (n=19) of respondents to the questionnaire did not disclose their epilepsy to their employer and 20% (n=20) of respondents had experienced a seizure at work. However, all four interview participants agreed that they would tell their employer about their epilepsy and this was mainly due to the safety issue.

When respondents were asked to state their level of agreement on the following statement *'Having epilepsy has a negative impact on employment prospects'*, 30% (n=29) strongly agreed, 27% (n=26) agreed, 22% (n=21) were undecided, 12% (n=11) disagreed and 9% (n=9) strongly disagreed with this statement. This is illustrated in the following table.

Table 18: Respondents level of agreement with the statement 'Having epilepsy has a negative impact on employment prospects'

	N	%
Strongly Agree	29	30
Agree	26	27
Undecided	21	22
Disagree	11	12
Strongly Disagree	9	9
Missing	14	
Total	**110**	

This table illustrates that 57% (n=55) of respondents either strongly agree or agree that epilepsy has a negative impact on employment prospects.

5.1.4 Driving Restrictions

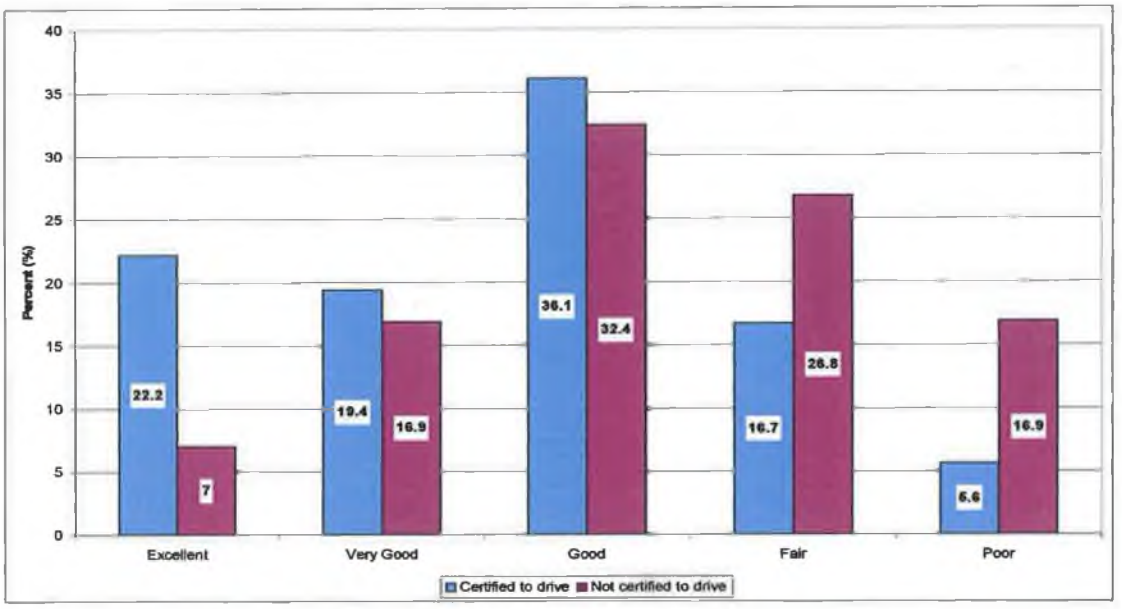
In the questionnaire, 44% (n=47) of respondents have a drivers licence. However, only 33% (n=36) are currently certified to drive. The following table illustrates the distillation of responses from the questionnaire with regard to how respondents feel not being able to drive affects their quality of life.

Table 19: Illustrates how driving restrictions affects quality of life

Driving	N	%
Lack of independence/ dependence on others constantly	21	40
Poor quality of life	11	21
Do not drive, fear I would cause an accident	3	6
Hard to get around/public transport insufficient	2	4
Would like to drive in future	4	7
Have adjusted to not being able to drive	2	4
Effects work/ability to rear children	2	4
It does not effect my life	8	15
Missing	57	
Total	**110**	

The findings illustrate that 40% of respondents feel that being unable to drive results in a lack of independence/dependency on others and 21% feel it results in poor quality of life. This suggests that driving restrictions have a negative impact on quality of life for people with epilepsy. The following figure compares how respondents rate their quality of life in relation to their participation in all aspects of society compared with whether respondents are certified or uncertified to drive.

Figure 12: Illustrates how respondents rate their quality of life in relation to their participation in all aspects of society compared with whether respondents were certified to drive or uncertified.



The above table illustrates that those certified to drive rate their quality of life in relation to participation in all aspects of society much higher than those who were not certified to drive. This suggests that driving restrictions have a negative impact on respondent's quality of life and this further impacts on their participation in society.

Respondents were asked to state their level of agreement with the following statement; *'Driving restrictions due to my epilepsy impact on my quality of life'*, 43% (n=41) strongly agreed, 21% (n=21) agreed, 13% (n=12) were undecided, 17% (n=16) disagreed and 6% (n=6) strongly disagreed with this statement. Therefore, 64% (n=64) of respondents either strongly agree or agree that driving restrictions due to their epilepsy impacts on their quality of life. Participant four in the focus group stated

> 'I would like to drive, everyone in my family drives. I wouldn't like to be the last, be the one left out (F4)'

In addition, all of the professionals interviewed agreed that driving restrictions have major implications for people with epilepsy. The CN stated

> '...this is the hardest thing we have to tell patients with epilepsy very often and obviously affects their quality of life, if you have to drive to work or if you have to drive your children to school or whatever it is, so this is a major issue'

Further, the CRO 1 stated

> 'The other main issue I would say living in this area is that a lot of people with epilepsy can't drive if they have seizures so public transport is chronic. There is no public transport really, you can get a bus to Dublin but you can't get a bus for five miles down the road or ten miles down the road, in to get shopping or so public transport is a big issue people have to get taxis and it costs a fortune. Otherwise they are left sitting at home doing nothing'

This was also highlighted by an interviewee

> 'Well up until two and a half years ago I was actually driving with my epilepsy because I can control my epilepsy. I know when I'm going to have a fit, I get a warning but I did have a car accident and then that was it. So that affected me, not being able to drive anymore....lucky enough I didn't hurt anyone else, only myself but that has affected my quality of life because if I need to go anywhere anymore I have to rely on people to take me' (P3)

When asked if she drove P2 said

> 'Yeah I didn't put that down on my thing, don't tell anyone...I didn't put down that I have seizures but really I suppose I don't have seizures so it wasn't really a full lie'

The above comments reiterate that driving restrictions impact negatively on quality of life of people with epilepsy. Lack of local public transport and the negative impact driving restrictions have on not just the person with epilepsy but their family as well were factors highlighted by professionals interviewed. One interviewee drove for years with her epilepsy and only stopped after an accident, which was caused by a seizure. Also, another interviewee had not mentioned on her driving application that she has epilepsy but felt that it was not necessary as her seizures are controlled. This suggests that due to the impact of driving restrictions on quality of life some people with epilepsy do continue to drive.

5.1.5 Stigma and epilepsy myths

In relation to stigma the majority of professional interviewees felt that stigma was still an issue but that things are improving all the time. This was described by the ESN who said

> 'In the past there were many myths and that out there but with more information becoming available there is less stigma attached'.

This was reiterated by one interviewee who said

> 'I don't think so nowadays but maybe going back 40 or 50 years ago I suppose there was a stigma to it...I know people can be cruel but I don't think so, not nowadays' (P3).

However, CRO 1 did not agree, she stated

> 'Yes there definitely is, people don't even like saying the word epilepsy...how you get rid of stigma is the important thing and that's through information, awareness, people talking about it, like people don't want to talk about their epilepsy either themselves and that in itself is saying something...it would be a big issue with employment'.

She highlighted this issue using an example she had come across recently whereby someone rang her about a relative who was working in a hospital.

> '...developed epilepsy and the employer who was a hospital told them that they couldn't possibly work if they had epilepsy because they would be working with the public...in this day and age, you think that you'd have some chance working in a medical environment...who are they trying to protect?'

The CN made the following point

> 'Of course it is the subjective stigma of the patient that may be worse...people feel stigmatised by it and that probably might be a bigger challenge than just other peoples attitudes...'

The majority of professionals agreed that stigma is still and issue but that it has improved over the last number of years. One professional disagreed with this. However, this may be due to her recently having dealt with a situation whereby an employer dismissed a staff member who had been diagnosed with epilepsy. In addition, one professional highlighted the point that stigma can only be eradicated through information and awareness. However, in her opinion people with epilepsy themselves don't like to talk about their condition. Moreover, the CN proposes that the subjective stigma of the patient may be worse. This suggests that in eradicating stigma it is vital to take into account the possibility that subjective stigma may be apparent in some people with epilepsy.

In relation to epilepsy myths, respondents to the questionnaire agreed that the general public hold myths in relation to epilepsy in 73% (n=74) of cases. The following table illustrates the distillation of responses from the questionnaire with regard to the myths respondents feel the general public hold in relation to epilepsy.

Table 20: Illustrates myths about epilepsy the general public hold reported by respondents

Myths	N	%
Holding a person down when seizure occurs	2	3
People look down on you	7	10
General public needs more information	15	21
Seen as contagious disease	3	4
People panic/do not know what to do	12	17
All epileptics affected by flashing lights	2	3
Swallow tongue/put spoon in mouth	11	15
Seen as mental illness	16	22
Think there is only one type of epilepsy	2	3
Employers reluctant to hire people with epilepsy	2	3
Missing	38	
Total	**110**	

Respondents to the questionnaire felt that the main myth about epilepsy held by the general public is, it is seen as a mental illness 22% (n=16). This table suggests that people with epilepsy feel the general public are not well-informed in relation to epilepsy. All four people with epilepsy who were interviewed felt that the general public hold myths about epilepsy. The following are some of the experiences reported by interviewees

> 'Yeah…like I was saying to somebody the other day that I was coming to talk to you today…she was like oh my god have you epilepsy and I was like yeah, its not that kind of epilepsy seriously like because you know what they are thinking. There going oh my god she's going to fall down and start shaking and frothing at the mouth…' (P2)

> 'There was an incident when I had my first child now this was in England and I was getting the Sunday papers and I had him in the pram and I actually took a seizure on the footpath and as I went down, at the time they used to be worse, and I pulled the pram down and I pulled my son out of the pram and he was only a couple of months old and as I lay on the footpath, I don't know how many people walked past me and didn't help or anything, with the baby, only for the help of an elderly man, I got home and the baby got checked out and he was ok but I lay there and nobody didn't want to know' (P3)

> '...Many times up in the disco here in...I took one and a heel of a shoe went into my eye, I nearly lost my eye and a girl came over and put something in my mouth which she shouldn't have, she should have just left me on my side so I was in the middle of the floor and I couldn't remember a thing but that was the lights again you know I shouldn't have been but when your in your teens you want to go out and enjoy yourself and be the same as everybody else (P1)'

These comments support the statistical evidence highlighted earlier (see table 20) that myths about epilepsy are still evident among the general public and may pose physical risks for people with epilepsy. This highlights the need for the public to be more informed with regard to all aspects of epilepsy. Ways in which the general public could be more informed about epilepsy according to the interview participants included

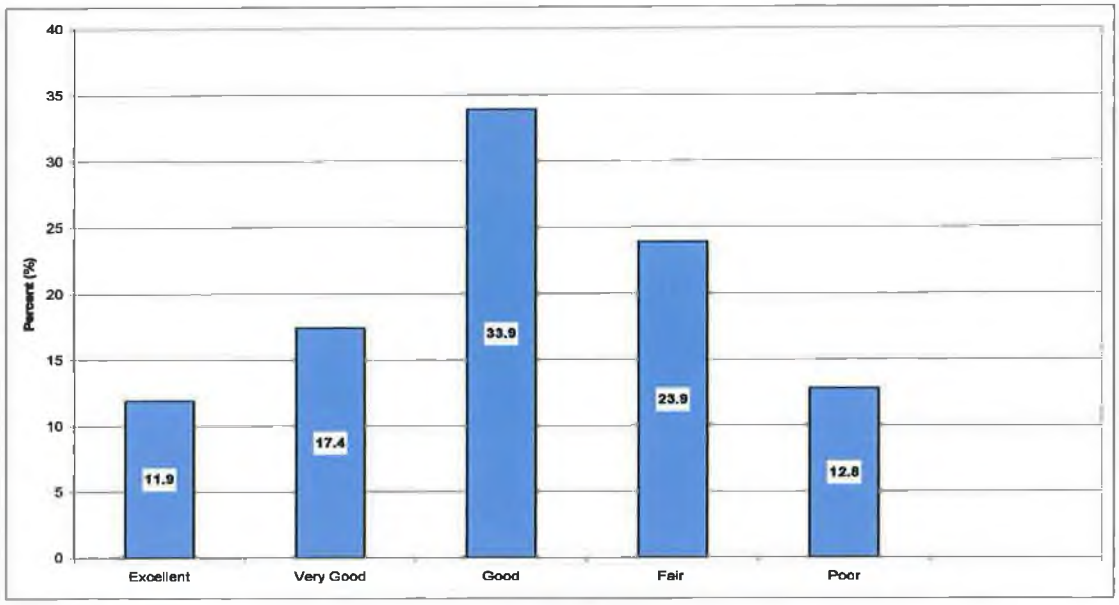
> '…if they can go in and talk about things in schools, epilepsy it is important because anyone can take one at any stage and it's not a pretty sight, it is scary (P1)'

> '…unless somebody gets out there and talks about it…made aware of it really…I suppose there's not enough television…adverts you know you gets adverts for depression and everything else…car accidents, drink driving…if there was something like that on the TV or on the radio…(P3)'

5.1.6 Quality of life

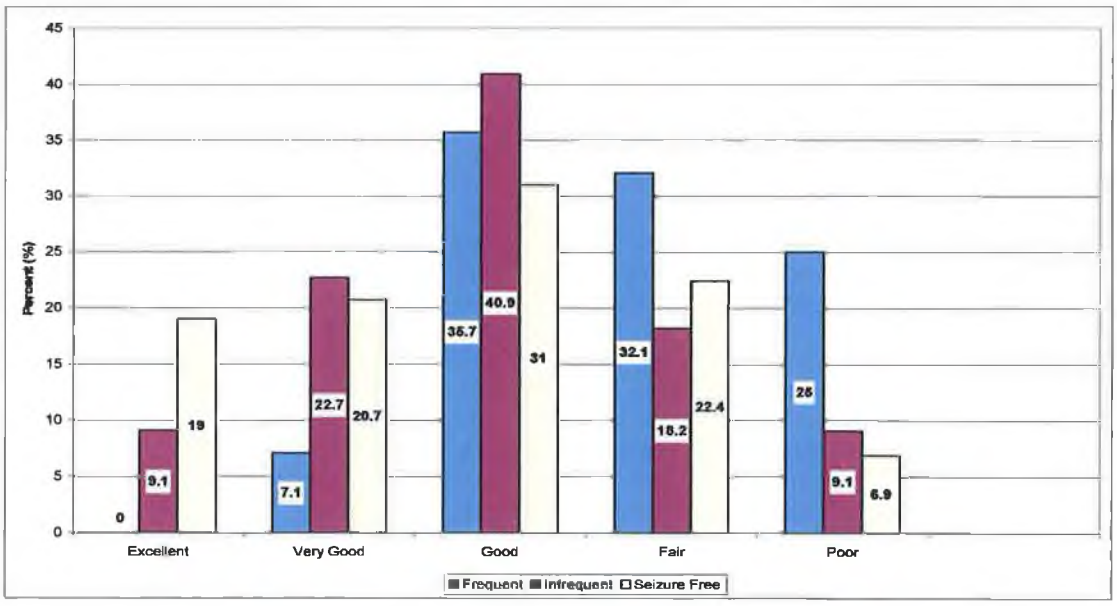
Respondents presently rated their quality of life in relation to their participation in all aspects of society as 'excellent' in 12% (n=13), 'very good' in 17% (n=19), 'good' in 34% (n=37), 'fair' in 24% (n=26) and 'poor' in 13% (n=14) of cases.

Figure 13: Illustrates how respondents rate their quality of life in relation to their participation in all aspects of society



This figure suggests that 37% of respondents describe their quality of life in relation to their participation in all aspects of society as 'fair' or 'poor'. The following figure compares how respondents rate their quality of life in relation to their participation in all aspects of society with respondent's seizure frequency.

Figure 14: Illustrates how respondents rate their quality of life in relation to their participation in all aspects of society compared with respondent's seizure frequency



This figure illustrates that no respondents with frequent seizures reported their quality of life in relation to their participation in all aspects of society as excellent. Further, those reporting fair and poor quality of life were more likely to have frequent seizures.

5.1.7 Conclusion

This chapter highlights a number of issues on quality of life and social impacts for people with epilepsy living in the Western region of Ireland. The findings suggest that respondents who were currently employed or self-employed were more likely to have achieved third level education and were more likely to describe their seizures as controlled. The majority of respondents, focus group participants and interview participants disclose their epilepsy to employers even though they feel their epilepsy does affect their employment prospects. Driving restrictions seemed to have a negative affect on respondent's quality of life and the majority of professionals agreed that driving restrictions have major implications for people with epilepsy. Moreover, the majority of respondents felt that the general public still hold myths about epilepsy and stigma appears to still be an issue but improving all the time. These issues are discussed in more detail in the next section of this chapter.

5.2 Discussion

It is apparent from the findings of this chapter that the guiding hypotheses of this research are confirmed. Firstly, quality of life issues for people with epilepsy are under-researched in Ireland. This was revealed by the apparent lack of Irish studies to correlate the findings of this research. Secondly, there are real social impacts for people living with epilepsy and thirdly, epilepsy impacts on the quality of life of those living with the condition. The confirmation of the two latter hypotheses is illustrated in the following discussion.

This study reveals that over half of respondents feel that their epilepsy has a negative affect on their social activities. There may be a number of factors which influence this. Firstly, driving restrictions may have an effect on respondent's ability to visit family and friends, attend functions and socialise.

Secondly, seizure frequency may have an effect as suggested by the CN who stated that it's not just the 'physical perils' of having a seizure but the 'embarrassment' and this can lead to 'secondary social phobia, where people with epilepsy stop going out, so they increase their social isolation'. Lastly, lifestyle issues may be a factor, adequate sleep and avoiding excess alcohol are very important for people with epilepsy. Moreover, this study suggests a link between seizure frequency and social aspects of quality of life. Respondents with frequent seizures were more likely to report their quality of life in relation to their participation in all aspects of society as fair or poor. This study supports Suurmeijer et al (2001) conclusion that health professionals should be aware of the implications of the psychosocial functioning of people with epilepsy and the role it plays in the attainment of a good quality of life.

It is suggested within the literature that people with epilepsy generally have lower educational attainment. Callaghan et al (1992) found the overall educational achievement of a sample of 343 people with epilepsy to be poor. Only 5% had achieved third level education. However, within this research the level of education was higher, with 28% of respondents achieving third level education. Although there was a higher rate of educational attainment in this study compared to Callaghan et al (1992) it is still considerably lower than that of the general population. The World Conference on Higher Education estimates that over 60% of the general population achieve third level education. Therefore, an important factor which should be taken into account within the educational system is the fact that the majority of both respondents to the questionnaire and the interviewees were diagnosed with epilepsy as young children or teenagers. This suggests the need for educational support specifically for people with epilepsy which was also highlighted by professionals interviewed within this research.

It has been suggested by numerous studies that people with epilepsy tend to be under employed or have a high rate of unemployment (Callaghan et al, 1992, Aldenkamp & Hendriks, 2000). Moreover, people with epilepsy report that employment is an area which affects their quality of life (Fisher et al, 2000, Jacoby et al, 2005). Within this research 25% of respondents to the questionnaire were unemployed. The majority of respondents were either employed 42% or self-employed 6% while the remaining respondents were retired, homemakers or students.

Jacoby (1995) found that generally people with well controlled epilepsy were less likely to experience problems with regard to employment. This was also the case within this research whereby of those currently in employment 73% describe their epilepsy as controlled. This was also highlighted by Collings & Chappell (1994) who found that being seizure free lessened the likelihood of unemployment. In contrast, Bautista & Wludyka (2007) did not have the same findings. They found that clinical factors such as seizure severity were not associated with employment. Carroll (1992) found that participants who had completed social skills training programmes specifically designed for people with epilepsy had positive implications in the areas of self-confidence and social skills. One interviewee within this research had completed the above mentioned course and felt that it 'definitely helped'. It provided him with more information about his condition and allowed him to make a more informed choice about his future with regard to further education and employment.

All professionals interviewed stated that driving restrictions was a major impact for people with epilepsy. This was reiterated by respondents of the questionnaire; 64% agreed or strongly agreed that it had a negative impact on their quality of life. This affect is also highlighted in the literature with Fisher et al (2000) stating it leads to job restrictions, feelings of dependency, school and other social restrictions. Moreover, in this study those certified to drive rated their quality of life in relation to participation in all aspects of society much higher than those who were not certified to drive. This suggests that people with epilepsy may require additional support in dealing with the consequences of driving restrictions.

Both Scambler & Hopkins (1986) and Westbrook et al (1992) found that 'disclosure' was an issue for people with epilepsy. The study by Scambler & Hopkins (1986) found that the majority of participants (72%) did not disclose their epilepsy to their employer. Therefore, it was surprising to discover that within this study only 22% of respondents had not disclosed their epilepsy to their employer. This is interesting considering over half of respondents felt that their epilepsy has a negative impact on their employment prospects. All interview participants stated that they would always disclose their epilepsy to an employer, their motivation for doing so was for safety reasons.

The majority of professionals felt that stigma was still an issue but that it was improving; two of the interviewees agreed with this but two did not. The two interviewees who did not agree felt that there is still a stigma attached to this condition, as one stated; the whole 'stereotypical person with epilepsy', 'they're dangerous or they're weird'. The reason for this could be in Scambler & Hopkins (1986) study which made a distinction between felt and enacted stigma. Jacoby (1994) revised this distinction in a sample of people with epilepsy and the results supported Scambler & Hopkins original distinction. This distinction was supported further by the CN who said that the subjective stigma of the patient may be worse, people feel stigmatised by their condition and that this is often a bigger challenge than other people's attitudes. In addition, Susman (1994) stated it is not the functional limitations of impairment but rather societal and social responses to it. Further, Baxendale (2007) found four main myths about epilepsy held by the general public. Firstly, calling an ambulance and secondly, foaming at mouth. Thirdly, put something in mouth and lastly, violence. Within this study the four main myths respondents felt the general public hold were only slightly different and included; seen as mental illness; general public needs more information; people panic and don't know what to do and swallow tongue/ put spoon in mouth. Baxendale (2007) found that one in three members of the general public in the U.K believe they should put something in the seizing person's mouth. Fifteen percent of respondents within this study felt that this myth was still evident among the general public in Ireland and one of the interviewees had actually experienced someone putting something in their mouth during a seizure. Therefore, people with epilepsy may be prone to potential physical harm. This suggests that more work needs to be done in eradicating these myths among the general public.

6.0 Quality of life and psychological impacts for people with epilepsy: Findings and discussion

6.1 Introduction

This chapter is divided into two sections. The first section will present the findings of this research in relation to quality of life and psychological impacts for people with epilepsy living in the Western region of Ireland. Details are provided in relation to participants understanding of and adjustment to the diagnosis of epilepsy, concerns about seizures, mood, memory and concentration. It also provides details on quality of life in relation to respondents overall well-being and provides details on respondent's subjective understandings of quality of life. The second section endeavours to discuss the findings of this research and how these relate to previous research carried out in the area. This section will also explore the guiding hypotheses of the research.

6.1.1 Understanding of and adjustment to the diagnosis of epilepsy

Within the questionnaire the respondents were asked to state their level of agreement with the statement '*I have felt discouraged by problems relating to my epilepsy*' 26% (n=26) strongly agreed, 38% (n=38) agreed, 11% (n=11) were undecided, 16% (n=16) disagreed and 8% (n=8) strongly disagreed with this statement. This is illustrated in the following table.

Table 21: Respondents level of agreement with the statement 'I have felt discouraged by problems relating to my epilepsy'

	N	%
Strongly Agree	26	26
Agree	38	38
Undecided	11	11
Disagree	16	16
Strongly Disagree	8	8
Missing	11	
Total	**110**	

This table illustrates that the majority of respondents (64%) have felt discouraged by problems relating to their epilepsy. This suggests that respondents may need additional support services in dealing with their epilepsy.

Interview participants were asked how they felt when they were diagnosed with epilepsy. The following are some comments made by interviewees about their diagnosis

> 'It was a bit scary at the start I suppose because I didn't really know what to expect and it was very bad at the start' (P2).

> 'I suppose at the time it originally, it was oh right now something they can have a go at me for but luckily it wasn't the case because when I did go back to school it was a case of that I found people that didn't really, wouldn't have gotten on with me or I wouldn't have called my friends, when someone did try to take a pop or have a go, they'd tell them to grow up or cop on like so kind of in that sense, I don't know maybe there could have been you know more, if I had known about Brainwave or something maybe that would have helped a bit more but in another way I think its better that I didn't because then I just had to decide for myself. I had two choices either 'pity me' or 'get up, get over it' (P4).

> 'I don't really think that epilepsy, its good to talk about it and that but the thing is there is worse out there that's the way I look at it, depression is worse, depression is the worst illness. I know this is an illness but what can you do, you just get on with it' (P1).

CRO 1 made the following point

> ...with a diagnosis of epilepsy the most important time really is the very beginning stages, you have the diagnosis that's when you have all the questions and if you get the right answers and you get the proper information you have a much better chance of getting on with your life and not letting epilepsy effect you, adjustment would be a big issue.

These comments are very interesting. The first two interviewees initially when diagnosed with epilepsy had negative attitudes. However, they felt that they had not received enough information in relation to their epilepsy at the time and 'didn't know what to expect'. This suggests that there is a close link with adequate accurate information upon diagnosis of epilepsy and adjustment which was also supported by the CRO. In addition, the third interviewee felt that epilepsy was not the 'worst' illness to have and you just 'get on with it'. Moreover, it is worth noting that the first two participants were diagnosed with epilepsy in adolescence and are currently in their early twenties.

The third interviewee was diagnosed with epilepsy at age four and is now in her thirties. This may suggest that there is a link between duration of epilepsy and adjustment.

6.1.2 Concerns about seizures

When asked if respondents worry about having a seizure 61% (n=66) agreed that they do worry, 39% (n=43) reported that they do not worry. When respondents were asked to state their level of agreement with the statement; *'I do not worry about having seizures'*, 6% (n=6) strongly agreed, 25% (n=25) agreed, 4% (n=4) were undecided, 36% (n=36) disagreed and 30% (n=30) strongly disagreed with this statement. This is illustrated in the following table.

Table 22: Respondents level of agreement with the statement 'I do not worry about having seizures'

	N	%
Strongly Agree	6	6
Agree	25	25
Undecided	4	4
Disagree	36	36
Strongly Disagree	30	30
Missing	9	
Total	**110**	

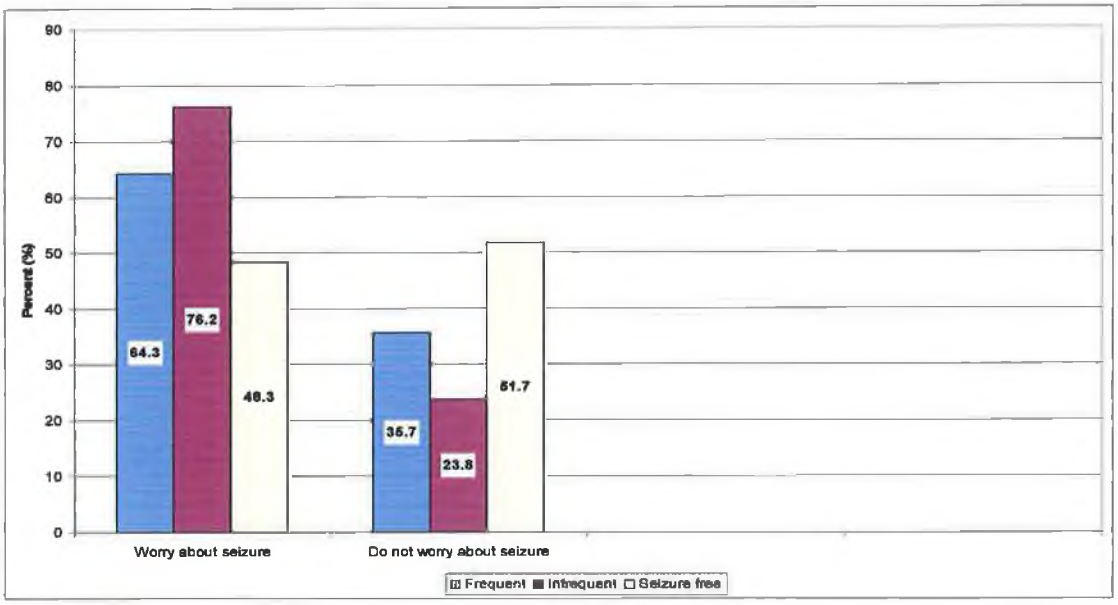
This table illustrates the majority of respondents do worry about having seizures. The following table illustrates the distillation of responses from the questionnaire with regard to the ways in which respondents feel worrying about having seizures affects their quality of life.

Table 23: Illustrates ways in which respondents feel worrying about having a seizure affects their quality of life

Worry affects quality of life	N	%
Being on my own when seizure occurs	9	15
Worry about losing drivers licence	2	3
Embarrassed/ afraid of having seizure in public	32	53
Restricts my activities	6	10
I worry sometimes	3	5
Worry about no medical help if seizure occurs	4	7
Worry affect seizure occurrence has on children/grandchildren	3	5
Worry about causing accident if seizure occurs	1	2
Missing	50	
Total	**110**	

The above table illustrates that embarrassment/afraid of having a seizure in public is the main worry which affects respondent's quality of life in relation to having seizures. Moreover, respondents reported the two most common myths about epilepsy the general public hold (table 20) were; seen as a mental illness (22%) and general public needs more information (21%). This suggests that there may be a link between the main worry which affects respondent's quality of life in relation to having seizures and the myths that they feel are still commonplace among the general public.

Figure 15: Illustrates whether respondents worry about having seizures compared with the frequency of their seizures



The above figure illustrates that a high proportion of respondents (48%) who are seizure free still worry about having seizures. This suggests that being seizure free does not necessarily reduce respondents worry about having seizures. With regard to the interviews one participant stated

> '...I do worry about it in the sense of that if I'm out somewhere and I feel something coming on, I worry about it then but as to worrying about it all the time as I said if you worry about it all the time, you'll do nothing so its just deal with it and if it happens then worry about it then and its just a case of making sure I can get somewhere that I'm not going to cause a scene' (P4).

P1 had similar worries because she found that 'excitement' could bring on a seizure for her. However, the other two interview participants said that they do not worry about their epilepsy, having seizures or injuring themselves.

6.1.3 Epilepsy and Mood

Respondents reported their epilepsy has an effect on their mood in 56% (n=60) of cases. Of those who felt that their epilepsy affected their mood, 43% were on one type of anti-epileptic medication, 17% were on two types and 40% were on three or more types of anti-epileptic medication.

Respondents were asked to state their level of agreement with the following statement '*My epilepsy does not affect my mood*, 8% (n=8) strongly agreed, 23% (n=23) agreed, 19% (n=19) were undecided, 33% (n=33) disagreed and 18% (n=18) strongly disagreed with this statement. This is illustrated in the following table.

Table 24: Respondents level of agreement with the statement 'My epilepsy does not affect my mood'

	N	%
Strongly Agree	8	8
Agree	23	23
Undecided	19	19
Disagree	33	33
Strongly Disagree	18	18
Missing	9	
Total	**110**	

This table illustrates that over half of respondents feel their epilepsy does affect their mood. The following table illustrates the distillation of responses from the questionnaire with regard to the ways in which respondents feel their epilepsy affects their mood.

Table 25: Illustrates affects epilepsy has on respondent's mood

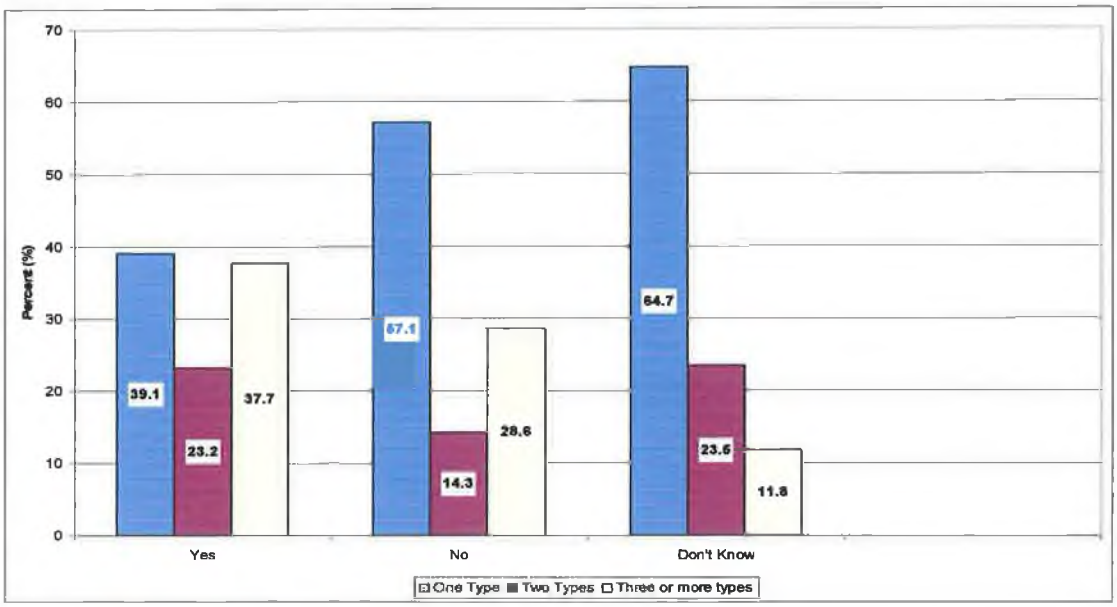
Effect on mood	N	%
Prone to bad mood swings	12	25
Mood tends to be up and down	11	23
Not sure	1	2
Seizure worry affects mood	5	10
Prone to feeling down or depressed	13	27
Lack of sleep affects mood	2	4
Medication affects mood	4	8
Missing	62	
Total	**110**	

The above table illustrates that 27% of respondents are prone to feeling down or depressed due to their epilepsy and 23% of respondents felt that their epilepsy increased the likelihood of them having bad mood swings. This suggests that half of respondents within this study feel their epilepsy negatively affects their mood.

6.1.4 Memory and concentration

Of the 110 respondents, 65% (n=70) feel that their epilepsy has an effect on their memory, 21% (n=23) reported that it had no effect on their memory. The following figure illustrates whether respondents feel their epilepsy affects their memory compared with how many types of anti-epileptic medications taken.

Figure 16: Illustrates whether respondents feel their epilepsy affects their memory compared with how many types of anti-epileptic medication taken



This figure illustrates that the majority of respondents who felt their epilepsy did not affect their memory were on one type of medication. However, of those who felt their epilepsy did affect their memory there seemed to be very little difference in the amount of medication taken. This suggests that there may be no link between the number of anti-epileptic medications and effects of epilepsy on respondent's memory. Therefore, indicating that it may not be medication but the epilepsy itself which affects respondent's memory. The following table illustrates the distillation of responses from the questionnaire with regard to the ways in which respondents feel their memory is affected by their epilepsy.

Table 26: Illustrates ways in which epilepsy affects respondent's memory

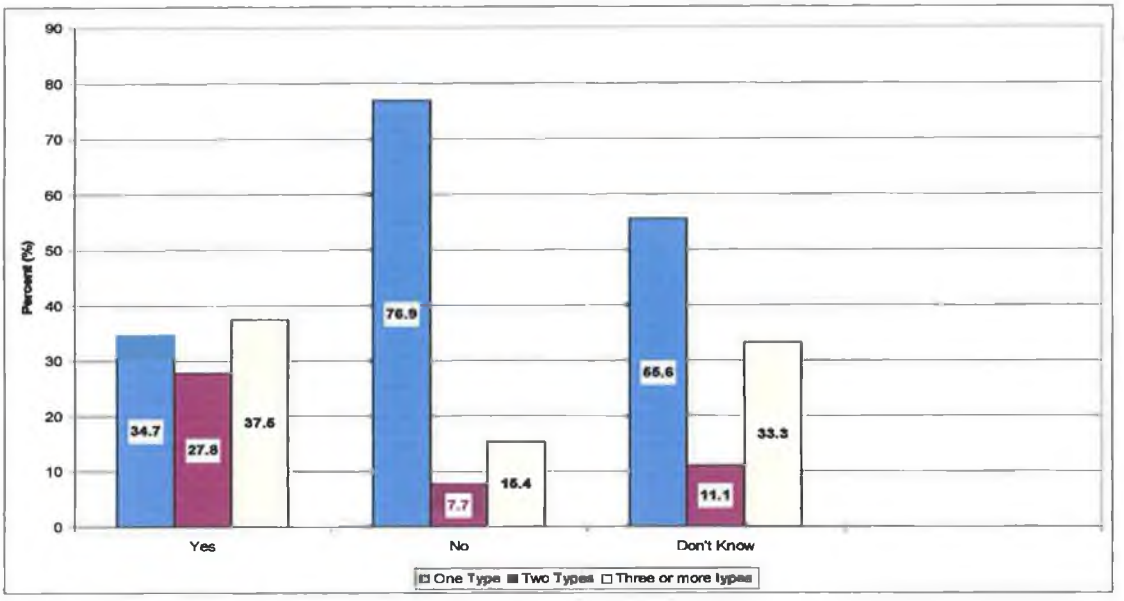
Memory	N	%
Taking medication effects my memory	6	11
Memory problems	15	26
Short term memory effected	11	19
Forgetfulness	17	30
Unsure if problems are due to epilepsy	3	5
Bad concentration	3	5
Long term memory effected	2	4
Missing	53	
Total	**110**	

This table illustrates the ways in which epilepsy affects memory defined by respondents. The two main ways in which respondents feel their epilepsy affects their memory are forgetfulness (30%) and memory problems (26%). This suggests there may be a need for early intervention and support for people displaying memory difficulties and may have implications for education and employment prospects. The ED also highlighted memory as an issue, as she explains

> …for the student group the memory thing is huge because it is quite difficult if you're short term memory is badly affected, it is quite difficult to learn new things and with a lot of the people I work with either the medication is affecting their short-term memory or the particular type of epilepsy they have is having an affect on their memory.

With regard to concentration, respondents reported epilepsy has an effect on their concentration in 68% (n=73) of cases.

Figure 17: Illustrates whether respondents feel their epilepsy affects their concentration compared with how many types of anti-epileptic medication taken



This figure illustrates that of those who feel their epilepsy does not affect their concentration 79% are on one type of anti-epileptic medication. Of those who said their epilepsy does affect their concentration there was not a significant difference in the amount of different types taken. This suggests that there may be no link between the number of anti-epileptic medications and effects of epilepsy on respondent's concentration. Therefore, indicating that it may not be medication but the epilepsy itself which affects respondent's concentration. The following table illustrates the distillation of responses from the questionnaire with regard to the ways in which respondents feel their epilepsy affects their concentration.

Table 27: Illustrates affects epilepsy has on respondent's concentration

Effect on concentration	N	%
Difficulty concentrating	11	19
Memory affects concentration	7	12
Worry about seizure occurrence affects concentration	4	7
Not sure	1	2
Mind wanders after short periods	20	34
Lack of sleep affects concentration	7	12
Medication affects concentration	9	15
Missing	51	
Total	**110**	

The above table illustrates that one of the main ways epilepsy effects respondents concentration is it causes their mind to wander after short periods 34% (n=20). This suggests that people with epilepsy may need additional support in dealing with concentration difficulties and may have implications for education and employment prospects.

6.1.5 Quality of life

Question 36 asked respondents in relation to their epilepsy would be most important in achieving best possible quality of life. Lists of answers were provided. The following table illustrates what respondents chose.

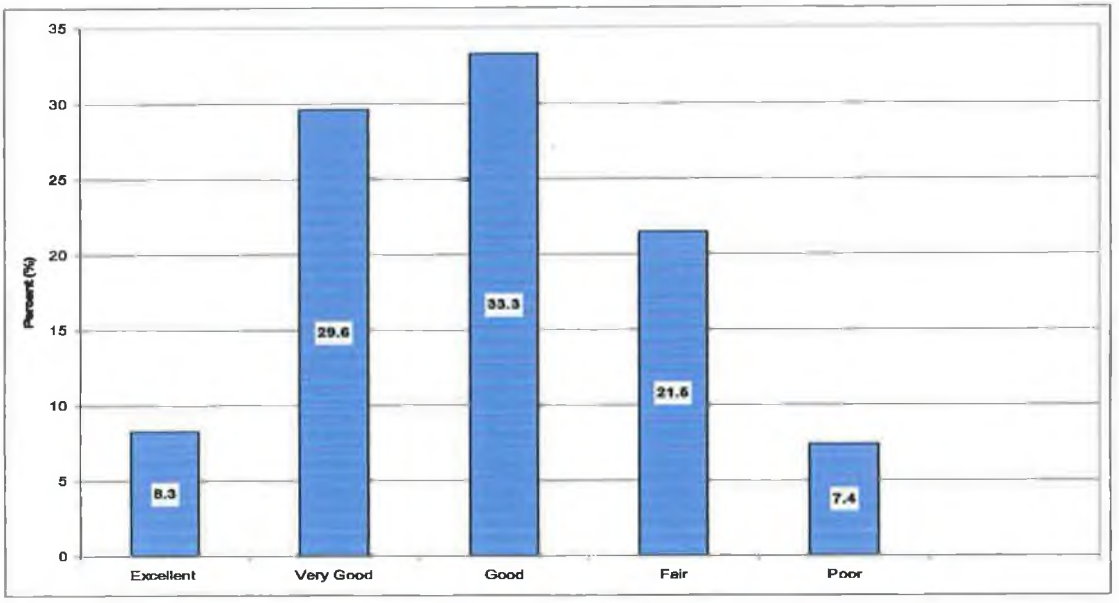
Table 28: Illustrates what respondents in relation to their epilepsy feel is important in achieving best possible quality of life

	N	%
Driving	28	26
Employment	21	20
Education	5	5
Independence	24	22
Safety	16	15
Medication side effects	9	8
Seizure control	51	48
Other	7	7
Total	**110**	

The above table illustrates that seizure control 48% (n=51) was the most important issue to respondents in achieving best possible quality of life, with driving next at 26% (n=28) while education was lowest at 5% (n=5). However, a number of respondents reported that if seizure control was achieved the other issues listed would improve as a result.

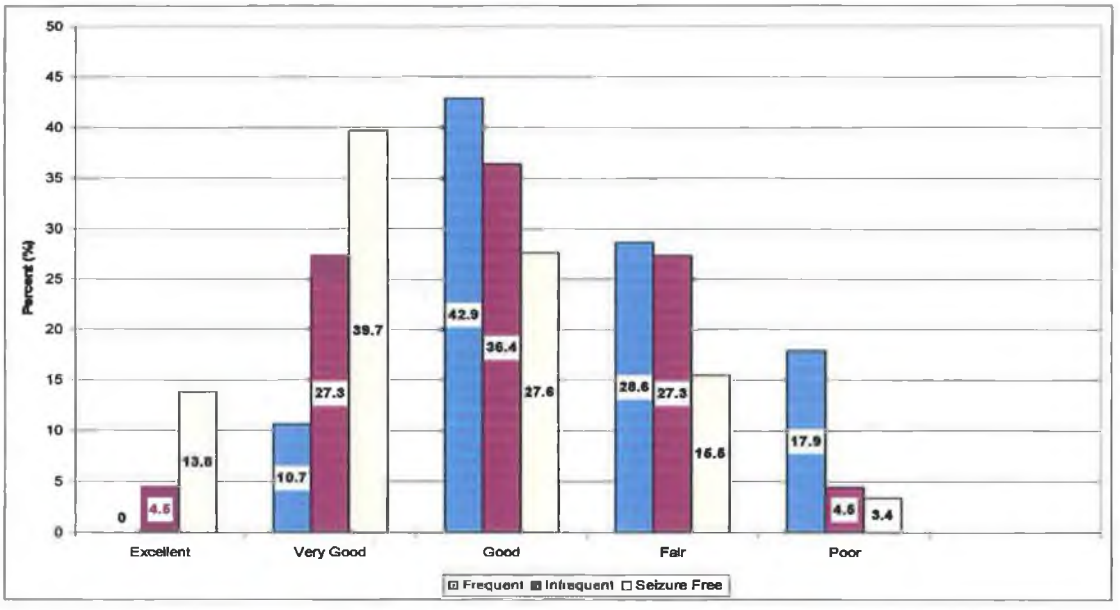
Respondents presently rated their quality of life in relation to their overall well-being as 'excellent' in 8% (n=9), 'very good' 30% (n=32), 'good' in 33% (n=36), 'fair' in 22% (n=24) and 'poor' in 7% (n=8) of cases.

Figure 18: Illustrates how respondents rate their quality of life in relation to their overall well-being



This table suggests that the majority of respondents report their quality of life in relation to their overall well being as very good and good. The following figure illustrates how respondents rate their quality of life in relation to their overall well-being compared with their seizure frequency.

Figure 19: Illustrates how respondents rate their quality of life in relation to their overall well-being compared with respondent's seizure frequency



The comparison of overall well being and seizure frequency is interesting. It suggests that those who reported their quality of life in relation to overall well being as excellent or very good were more likely to be seizure free. Respondents who reported their quality of life in relation to overall well being as poor were more likely to have frequent seizures i.e. more than one a month. This suggests a link between seizure frequency and how respondents rate their quality of life in relation to their overall well-being.

6.1.6 Subjective understandings of quality of life

Question 39 asked respondents to 'Explain what quality of life means to you' which resulted in a wide variety of answers. However, the majority of respondents listed some of the following; 'happiness', 'health', 'independence', 'not worrying about getting seizures', and 'control'. The following are other responses reported

> 'Quality of life for me is to be able to live my life and not to be living a lie i.e. concealing my epilepsy' (IDNO: 6)
>
> 'Question 4 was hard to answer I was not diagnosed until I was 36, but when I look back I had it since I was very young, but my parents wouldn't believe me. I am an only child of elderly parents and they convinced themselves I was perfect' (IDNO: 16).
>
> 'I am new to epilepsy in that my first seizure was in 2006 and then 2007 so I am still learning. I did not accept it at first – thinking 'I don't have epilepsy' – I am 50 now. In my case I am sure alcohol, stress and lack of sleep brought on my seizures' (IDNO: 49).
>
> 'I know very little about my type of seizure-what brought it on-will I ever get a big one again or will the medication take care of that. My MRI was clear but my EEG showed epilepsy, is this normal? (IDNO: 54)
>
> 'Please use these research findings to increase awareness among the public and employers about what it means to have epilepsy. Sometimes the biggest burden of epilepsy is living with other people's attitudes to it (IDNO: 75)
>
> 'The ability to do everything you want and achieve all of your goals and ambitions in life. This is not always possible due to epilepsy' (IDNO: 83)
>
> 'To live independently and have control over my life and finances' (IDNO: 87)
>
> 'Sometimes I get very frustrated with people especially the medical people, and feel I'm just being treated as another number when I try to get answers about my condition' (IDNO:93).

The above comments emphasises the subjective nature of quality of life and highlights issues around concealment, independence, lack of information, stigma and adjustment to the diagnosis of epilepsy. In contrast to the above statements, the following are other comments made

> 'Epilepsy has had a big effect on my life as a child and a teenager growing up. I have gone back to adult education now, I did well. I think I leaned on the fact that I have epilepsy not to do a lot in life that I could have done and I let it control me. It may be a bit late now but I don't let the fits take over my life anymore and I live life to the full' (IDNO: 53).

> 'Perhaps I am naïve or just very lucky to have such wonderful support around me, but in today's world, having epilepsy should not have an impact on an adult's quality of life. Perhaps for someone with uncontrolled seizures, spending a lot of time in hospital will naturally have an impact on their quality of life but with all the advancements in the medical world, there are no reasons why most epileptics cannot enjoy a full, happy, healthy life' (IDNO:86).

These comments suggest that support services and adequate information regarding all aspects of epilepsy may lead to positive adjustment to the diagnosis and therefore, may improve quality of life for people with epilepsy.

6.1.7 Conclusion

This chapter highlights a number of issues on quality of life and psychological impacts for people with epilepsy living in the Western region of Ireland. The findings suggest that there may be a link with adequate accurate information upon diagnosis of epilepsy and adjustment. This study suggests that being seizure free does not necessarily reduce respondents worry about having seizures. In addition, the findings indicate that over half of the respondents felt that their epilepsy had a negative effect on their mood, memory and concentration. Moreover, this study suggests a close link between seizure frequency and how respondents rate their quality of life in relation to their overall well-being. These issues are discussed in more detail in the next section of this chapter.

6.2 Discussion

It is apparent from the findings of this chapter that the guiding hypotheses of this research are confirmed. Firstly, quality of life issues for people with epilepsy are under-researched in Ireland. This was evident in the apparent lack of Irish studies in which to relate the findings of this research. Secondly, there are real psychological impacts for people living with epilepsy and thirdly, epilepsy impacts on the quality of life of those living with the condition. The confirmation of the two latter hypotheses is revealed in the following discussion.

The importance of patients understanding and adjustment to epilepsy has been highlighted by many authors (Baker et al, 1999, Jarvie 2001). Within this study the CRO felt that the most important time is the very beginning after you get the diagnosis. She suggests that if questions are accurately answered and information provided at this crucial stage, it can assist with positive adjustment to the diagnosis. Interview participants had different opinions and experiences. One interviewee said 'it was a bit scary' and she 'didn't really know what to expect'. In contrast to this another interviewee was only worried about the reaction of his classmates and peers at school. He also felt it was better that he did not know about Brainwave as it forced him to make a decision for himself as to how to handle the diagnosis, saying he had two choices 'pity me' or 'get up, get over it'. Another interviewee felt that there are worse illnesses 'out there' and you just 'get on with it'. Further, Velissaris et al (2007) found that participants tried to find the 'cause' of their seizure, but that it often lacked a medical basis. Within this study two of the interviewees proposed the cause of their seizures but unlike Velissaris et al (2007) their explanations seemed to have a medical basis. The first attributed her seizures as coinciding to her menstrual cycle. The second felt that had she not taken medication prescribed for migraines she would not have epilepsy; she felt that the migraine medication had triggered her seizures. However, another interviewee stated a bullying incident at school had triggered his epilepsy which was later discovered to be pseudo-epilepsy.

A high proportion of respondents reported epilepsy as affecting their memory and concentration. This study did not find a link between memory and concentration difficulties with anti-epileptic medication.

Therefore, this indicates that these problems may stem from the epilepsy itself and not side-effects of medication which has previously been reported as a factor (Baker, 2006). Moreover, Specht (2001) suggests people with epilepsy who have achieved seizure control still suffer from negative consequences of their epilepsy. This study confirms this as only 54% of respondents who are seizure free rate their quality of life in relation to overall well-being as excellent or very good.

Harden et al (2007) found an association between seizure severity and the development of worry and anxiety in people with epilepsy. In contrast within this study when seizure frequency was compared with the 61% of respondents who do worry the data showed that 48% were seizure free. This suggests that being seizure free does not reduce respondents worry about having seizures and supports Fisher et al (2000) who suggests that the unpredictability of epilepsy is a key factor in how people perceive their quality of life. Moreover, Loring et al (2004) suggest that symptoms of depression and seizure worry are the most important factors affecting quality of life in people with epilepsy.

The literature suggests a high incidence of depression among people with epilepsy (Cramer 2002 & Gilliam et al, 2004). Within this study 56% of respondents reported that their epilepsy affected their mood. Their description of how it affected their mood was interesting; 27% reported feeling down or depressed and 25% reported being prone to mood swings due to their epilepsy. Further research is warranted to determine the prevalence of depression in people with epilepsy and how this ultimately affects their quality of life.

With regard to pseudo-epilepsy Mazza et al (2006) found that it usually manifests itself between 20 and 30 years, almost a third of patients are women and it is usually linked to a traumatic experience. This study had similar findings, the interviewee with pseudo-epilepsy was male, 24 years of age and the development of his pseudo-epilepsy was linked to bullying at school.

The comments made by respondents indicating what quality of life means to them are interesting as they highlight the subjective nature of quality of life assessment. This study supports Jacoby (2000) who suggested that because quality of life is an individual construct it can only be measured by taking into account people with epilepsy's own values, feelings and preferences. The majority of respondents listed 'happiness' 'health' 'independence' 'not worrying about getting seizures' and 'control' as most important issues regarding what quality of life means to them. Moreover, the comments made by respondents highlight issues around concealment, adjustment, lack of information and stigma. Although there were positive comments the vast majority were negative indicating the importance of assessing quality of life and the physical, social and psychological impacts of epilepsy within an Irish context.

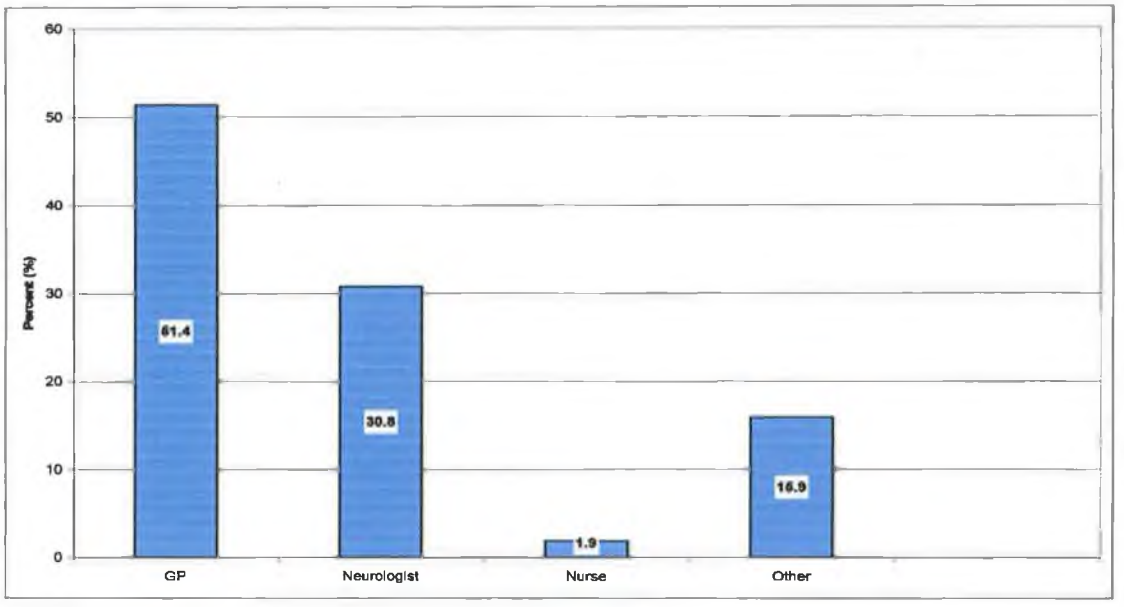
7.0 Universal quality of life impacts for people with epilepsy: Findings and Discussion

7.1 Introduction

This chapter is divided into two sections. The first section will present the findings of this research in relation to universal quality of life impacts for people with epilepsy. These impacts are common threads which overlap with physical, social and psychological implications of epilepsy but may also have implications for social and health policy. Details are provided on neurological services, support services and epilepsy information. The second section endeavours to discuss the findings of this research and how these relate back to previous research completed in the area.

7.1.1 Neurological services

Figure 20: Illustrates who carried out respondent's initial assessment



The above figure illustrates that over half of respondents were first seen by a GP in relation to their epilepsy. This may suggest the importance of GPs having regular and updated training with regard to all aspects of epilepsy.

Respondents were seen by a Consultant Neurologist in 87% (n=96) of cases. Upon application to see a Consultant Neurologist, the following table describes how long respondent's waited for an appointment.

Table 29: Illustrates months respondents waited for appointment to see a Consultant Neurologist

Months	N	%
Under 5 Months	35	39
6 months – 1 year	36	41
13 months – 2 years	11	12
Over 2 years	7	8
Missing	21	
Total	**110**	

This table suggests that the majority of respondent's were seen by a Consultant Neurologist within one year. However, when respondents were asked to state their level of agreement with the statement; *'The waiting times to see a consultant neurologist are too long'*, 55% (n=55) strongly agreed, 22% (n=22) agreed, 6% (n=6) were undecided, 13% (n=13) disagreed and 4% (n=4) strongly disagreed with this statement. This is displayed in the following table.

Table 30: Respondents level of agreement with the statement 'The waiting times to see a consultant neurologist are too long'

	N	%
Strongly Agree	55	55
Agree	22	22
Undecided	6	6
Disagree	13	13
Strongly Disagree	4	4
Missing	10	
Total	**110**	

This table shows that although the majority of respondents within this study were seen by a Consultant Neurologist within one year, 77% either strongly agree or agree that waiting times are too long. This was also highlighted in the focus group, with one participant stating

> 'It's very difficult to get, the lack of neurologists in this country is ridiculous' (F1).

The interview participants were all seen by a Consultant Neurologist. P4 explains his situation with regard to waiting times

> 'I actually didn't see a neurologist until I was nearly nineteen...what happened was my paediatrician at the time who was about to finish off with me diagnosed it. So what he decided to do was because the waiting list is so long and I could be waiting forever to see a neurologist and there was so few of them in the west of Ireland that he kept me on his patient list rather than hand me over to the adult section just until I was eighteen. So by then I should have been able to get a neurologist appointment'.

This was further highlighted by the professionals with the CN stating

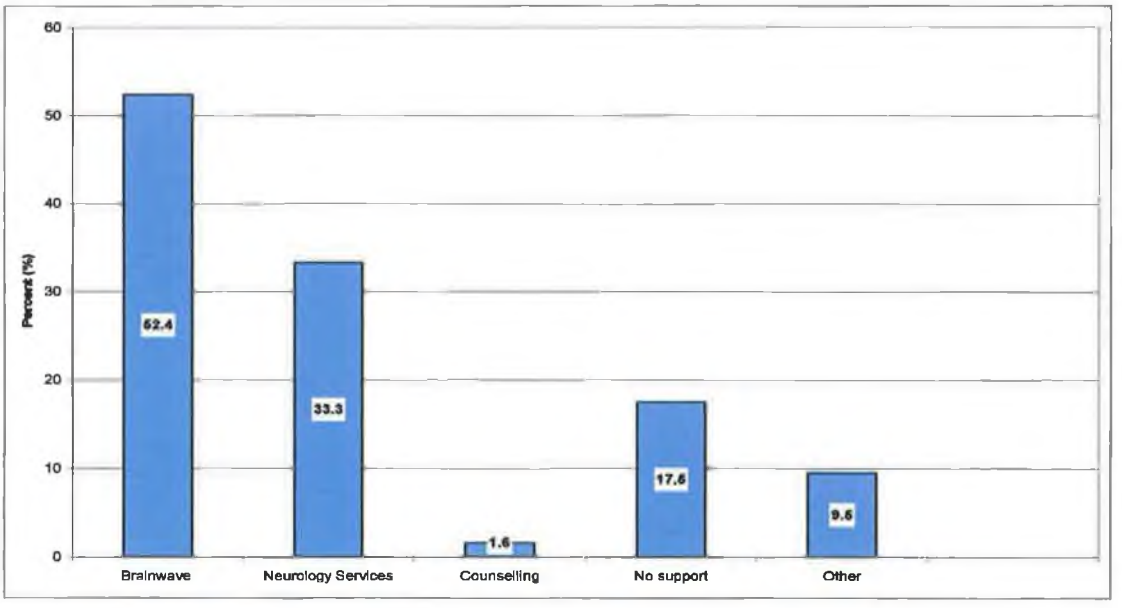
> '...waiting lists for neurology in this country are about two years or more so that is a big barrier'. While the ED stated '...it's not unknown for people to wait a year and a half for an appointment and that's bad enough but it's very frightening for somebody if their seizures are changing and their not sure why or what's going on, so they can be very insecure and vulnerable and that is difficult'.

The majority of respondents, focus group participants and interview participants all felt that the waiting times to be seen by a Consultant Neurologist are too long. This suggests the need for more experts in the area to reduce the waiting times and tackle the problem of misdiagnoses such as the one described by P4.

7.1.2 Support services

Upon diagnosis 49% (n=53) of respondents were offered support services. The following figure illustrates the support services that were offered to the above respondents.

Figure 21: Illustrates support services offered to respondents upon diagnosis



This figure illustrates that 18% of respondents were offered no support at all upon the diagnosis of their epilepsy. This suggests that there may need to be more emphasis on offering support services to people with epilepsy, particularly upon diagnosis of the condition. In addition, respondents were asked to state their level of agreement with the statement, *'There are adequate support facilities for people with epilepsy'*, 7% (n=7) strongly agreed, 21% (n=21) agreed, 17% (n=17) were undecided, 30% (n=31) disagreed and 25% (n=25) disagreed with this statement. This is illustrated in the following table.

Table 31: Respondents level of agreement with the statement 'There are adequate support facilities for people with epilepsy'

	N	%
Strongly Agree	7	7
Agree	21	21
Undecided	17	17
Disagree	31	30
Strongly Disagree	25	25
Missing	9	
Total	**110**	

This table suggests that over half of respondents believe that support facilities for people with epilepsy are inadequate. Within the interviews with professionals in the field of epilepsy there was a question relating to what support services are offered to people upon a diagnosis of epilepsy. The CN remarked that this was

> '...quite variable and would also depend on who is giving you the diagnosis...in a busy outpatient clinic it can be very difficult...because not everybody has the time'

The ESN listed supports offered as

> '...access to neurologist, access to clinical nurse specialist in epilepsy...the neuro-psychologist...and then psychiatry if necessary'.

When asked whether these services would be available nationwide, the ESN said

> 'No not in all hospitals'.

The comments made by professionals in the field of epilepsy were interesting. The Consultant Neurologist maintained that support services are variable and would depend on who is giving the diagnosis as 'not everybody has the time'. In contrast, the ESN listed a wide range of support services available but when probed further on this issue said that these services are not available 'in all hospitals'. This suggests that the amount of support services a person with epilepsy receives depends on the hospital they attend. Within the interviews P2 was offered no support while P1 and P3 said their parents were 'probably' offered support. P4 said he received some support initially but when he was re-diagnosed five years later he received more support facilities.

7.1.3 Epilepsy Information

Respondents to the questionnaire were asked to state their level of agreement with the statement; *'I have received sufficient information in relation to all aspects of my epilepsy'*, 19% (n=20) strongly agreed, 39% (n=39) agreed, 15% (n=15) were undecided, 15% (n=16) disagreed and 12% (n=12) strongly disagreed with this statement. This is illustrated in the following table.

Table 32: Respondents level of agreement with the statement 'I have received sufficient information in relation to all aspects of my epilepsy'

	N	%
Strongly Agree	20	19
Agree	39	39
Undecided	15	15
Disagree	16	15
Strongly Disagree	12	12
Missing	7	
Total	**110**	

This table suggests that almost one-third of respondents feel that they have not received sufficient information in relation to all aspects of their epilepsy. In the focus group one participant stated

> 'The doctor or neurologists they're more into speaking doctors' language instead of in English. I would have done a lot of reading (F1)'.

With regard to those participating in the interviews P1 and P2 sought information themselves through pamphlets and the use of the internet. Further, one interviewee stated

> '...no I probably wasn't either given that much information about it, probably my mother and father would have got the information at the time but I didn't really ask questions (P3)'.

This was reiterated by focus group participant who said

> '...I was diagnosed as a kid, the doctors explained to them and they only explained to me when I was fourteen, I didn't know what was wrong with me...(F3)'

Another factor regarding information was highlighted by a professional who stated

> '...I still get people telling me that the doctor told them that they have to wait three years for their drivers licence...that's down to one year' (CRO 1).

These comments reiterate the need for providing accurate and understandable information to people with epilepsy and further highlight the need for up-dated training for professionals dealing with epilepsy.

7.1.4 Conclusion

This chapter highlights a number of issues relating to universal quality of life impacts for people with epilepsy. Firstly, the majority of respondents to the questionnaire, focus group participants and interview participants all highlighted that waiting times to see a Consultant Neurologist are too long and this can impact negatively on quality of life. Secondly, less than half of respondents were offered support services when they were diagnosed. Thirdly, almost one third of respondents felt that they were not sufficiently informed in relation to all aspects of their epilepsy. These issues are discussed further in the next section of this chapter.

7.2 Discussion

The majority of respondents to the questionnaire felt that the waiting times to see a Consultant Neurologist are too long. This was also highlighted by both groups of interviewees; the professionals and people with epilepsy. The Comhairle na nOspideal Report (2003) recommended a target of 39 Consultant Neurologists, with an interim target of 29. However, the actual number of Consultant Neurologists in Ireland at present stands at 19.

Therefore, people with epilepsy can wait for up to two years for an appointment which can have an enormous affect on a persons quality of life and leaves people feeling 'very insecure and vulnerable'. This gap in provision was highlighted by one interviewee who was diagnosed with epilepsy but due to waiting times to see a neurologist his paediatrician 'kept him on his books' until an appointment came up. The interviewee was prescribed medication for his epilepsy which he took for the following four or five years. Subsequently he was taken into hospital for tests whereby doctors found that there was no abnormal brain functioning during his seizures which lead to a re-diagnosis of non-epileptic seizures or pseudo epilepsy. In other words, as he describes 'it's psychologically based'. This type of epilepsy cannot be treated by anti-epileptic medication so he was taken off it. However, he still deals with the side effects of this medication. The NAI standards of care recommend all people should have their neurological condition efficiently investigated, diagnosed and treated by a relevant specialist. This suggests that if he had been treated as the NAI recommends from the beginning his epilepsy would not have been misdiagnosed, he would not have been put on medication and suffer side effects and his correct treatment would have started at an appropriate time based on his individual diagnosis and prognosis. Moreover, misdiagnoses also result in huge costs to the state. According to the National Institute of Clinical Excellence cited by the Joint Epilepsy Council (JEC: 2005) epilepsy misdiagnosis rates in the U.K are between 20-31% and result in an annual cost of approximately £160 million.

Furthermore, Neligan et al (2006) suggests a need for greater communication between GPs and neurological services. This would allow information regarding advances and changes in clinical neurological services to be accessible to GPs and so lead to the successful management of people with epilepsy. This study supports Neligan et al (2006) considering over half of respondents reported their GP had carried out their initial assessment and waiting times to be seen by a Consultant Neurologist are too long.

It is surprising that less than half of respondents were offered support services upon diagnosis of epilepsy. A factor that could contribute to this is the lack of allied health professionals in the field of epilepsy more specifically the chronic shortage in the Western region of Ireland.

This was supported by the CN who said support services are variable and dependent on who is giving the diagnosis as 'not everybody has the time'.

Hart et al (1995) and Chappell et al (1998) both found that people with epilepsy lacked information about their epilepsy. This was also found within this study as one third of respondents felt inadequately informed in relation to all aspects of their epilepsy. Two of the interview participants sought information themselves through pamphlets and the internet. This may suggest that they had not received enough information. A number of focus group participants and two interviewees were diagnosed with epilepsy in early childhood but they thought their parents 'probably' received information. Moreover, one focus group participant said that his parents did not explain his epilepsy to him until he was fourteen and he 'didn't know what was wrong' until then. This suggests that parents may require additional support in explaining epilepsy to their children. The findings also indicate that information given to people with epilepsy needs to be straightforward and understandable to the individual and appropriate time given to answer any questions people may have.

7.3 Conclusion

The previous four chapters present the findings and discussion of this research achieved through the application of the chosen research methods which have previously been explained and justified in the methodology chapter.

On the basis of the findings of this research the guiding hypotheses are confirmed. Firstly, quality of life issues for people with epilepsy are under-researched in Ireland. This was revealed in the apparent lack of Irish studies relating to quality of life in which to correlate the findings of this research. Secondly, there are real physical, social and psychological impacts for people living with epilepsy and thirdly, epilepsy impacts on the quality of life of those living with the condition. The confirmation of the two latter hypotheses was revealed in the discussion of the findings of the research in each of the four chapters. Moreover, universal quality of life impacts for people with epilepsy highlighted common threads which overlap with physical, social and psychological implications of epilepsy but may also have implications for social and health policy.

8.0 Conclusion and recommendations

8.1 Introduction

This study highlighted the implications of having epilepsy and explored quality of life issues for people with epilepsy, specifically those living in the western region of Ireland. This chapter outlines the main conclusions and recommendations drawn from the findings of this study and is divided into four sections. The first section concludes and makes specific recommendations relating quality of life and physical impacts for people with epilepsy. The second section concludes and makes specific recommendations relating to quality of life and social impacts for people with epilepsy. The third section concludes and makes specific recommendations relating to quality of life and psychological impacts for people with epilepsy. Finally, the fourth section concludes and makes specific recommendations relating to universal quality of life impacts for people with epilepsy.

On the basis of the findings of this research the guiding hypotheses are confirmed. Firstly, quality of life issues for people with epilepsy are under-researched in Ireland. This was revealed in the apparent lack of Irish studies relating to quality of life in which to correlate the findings of this research. Secondly, there are real physical, social and psychological impacts for people living with epilepsy and thirdly, epilepsy impacts on the quality of life of those living with the condition. The confirmation of the two latter hypotheses was revealed in the discussion of the findings of the research in previous four chapters. Furthermore, universal quality of life impacts for people with epilepsy highlighted common threads which overlap with physical, social and psychological implications of epilepsy but may also have implications for social and health policy.

8.2 Quality of life and physical impacts for people with epilepsy

This study suggests that there is a relationship between seizure frequency and employment status. Although almost half of respondents within this study were seizure free, it has been suggested that between 70-80% of people with epilepsy should be seizure free.

However, this may not be the case with professionals interviewed stating this is not the case and the figure is more likely to be 60% which leaves a 20% fallout. The issue of seizure control was also highlighted within this study as 48% of respondents described this as the most important issue in achieving best possible quality of life. However, this study suggests that even those whose describe themselves as being 'seizure free' still suffer negative consequences. The findings of this study suggest that the issue of seizure control needs to be addressed.

- It recommends regular reviews of patients with specific regard to those whose seizures are uncontrolled but continuing regular review of all patients regardless of their seizure frequency.

The findings of this study indicate that almost 40% of respondents do not participate in sport/leisure activities as a direct consequence of their epilepsy or fear of seizure. However, the findings also indicated that of those who reported their epilepsy effects their sport/leisure activities, 58% did not feel that there were sufficiently informed in relation to this.

- Therefore, it is recommended that people with epilepsy should be more informed in relation to their participation in sport/leisure activities and allied health professionals who may not have the adequate information in relation to this should direct the person to Brainwave, the Irish Epilepsy Association.

8.3 Quality of life and social impacts for people with epilepsy

Overall, driving restrictions were one of the main issues within this study. The findings suggest that these restrictions negatively affect the quality of life of people with epilepsy and results in feelings of dependency and may also limit social activities. In addition, respondents who were certified to drive rated their quality of life in relation to participation in all aspects of society much higher than those who were not certified to drive. The findings of this study suggest there are two main considerations which may need to be addressed with regard to driving restrictions.

- Firstly, it recommends adequate accurate information in relation to driving restrictions be provided to every individual with epilepsy.

- Secondly, it recommends the provision of additional support for people with epilepsy to deal with the consequences of driving restrictions which negatively impact on their quality of life.

This study suggest that although educational attainment of people with epilepsy seems to have improved, overall it remains much lower than that of the general population. In addition, it was apparent that the majority of respondents were diagnosed with epilepsy as young children and teenagers. Moreover, one interviewee highlighted the positive implications of a social skills training programme specifically for people with epilepsy which he completed. The findings of this study suggest that there are a number of implications which need to be considered.

- Firstly, it recommends the availability of support services for children and teenagers within the educational system.
- Secondly, it recommends the need for awareness and first aid training relating to epilepsy to be an integral part of vocational training of teachers and those working in the educational system.
- Thirdly, it recommends that provisions be devised which support and encourage people with epilepsy through either third level education or social skills training programmes.

In the area of employment this study found a link between seizure frequency and employment. Respondents who described their seizures as controlled were more likely to be in employment. Within this study 25% of respondents were unemployed which supports previous research in the area indicating that people with epilepsy tend to be under-employed.

- It is therefore recommended that awareness campaigns relating to epilepsy should be geared toward employers. It also recommends the setting up of nationwide social skills training programmes specifically designed for people with epilepsy similar to the two already in existence in Ireland.

Stigma was still seen as an issue for people with epilepsy within this study. Although, it may perhaps suggest that this stigma may be perceived by the person with epilepsy themselves and may not be as prevalent within the general population.

- This study recommends the development of awareness campaigns regarding epilepsy be more common and should incorporate the use of mass media such as advertising campaigns similar to those currently running dealing with drugs awareness, and alcohol and young people.

8.4 Quality of life and psychological impacts for people with epilepsy

Over half of respondents to this study reported that their epilepsy affects their mood. This was apparent in two main ways. Firstly, they suggested their epilepsy causes them to be prone to 'feeling down or depressed' and secondly, they suggested it causes them to be prone to what they described as 'bad mood swings'.

- This study recommends research into the establishment of the exact prevalence of depression in people with epilepsy. This is essential in order to provide adequate services to deal issues which may arise for people with epilepsy relating to this area.

Furthermore, this study found that there may be a possible link between adequate accurate information upon diagnosis of epilepsy and adjustment and a possible link between duration of epilepsy and adjustment to the diagnosis.

- It is therefore recommended that the importance of adequate and accurate information upon a diagnosis of epilepsy be highlighted to professionals working in this area. Regardless of possible time constraints each individual should be given the appropriate time to receive this information and ask any questions. This could be further promoted through the establishment of support groups nationwide.

This study found that a high proportion of respondents reported their epilepsy as affecting their memory and concentration.

- Therefore, it is recommended that early intervention is needed where possible relating to these two issues such interventions could include strategies to assist in memory function.

- It also recommends that policies such as the above be put in place for children, teenagers and young adults within the educational system which could also map the person's progression through education. Therefore providing a clearer picture of how memory and concentration difficulties manifest for people with epilepsy.

8.5 Universal quality of life impacts for people with epilepsy

The universal quality of life impacts for people with epilepsy issues that were highlighted in this study are ones that have been emphasised for a number of years. Nonetheless, they are noted again within this study. The lack of neurologists is a major issue for people with epilepsy and leads to people waiting anything up to two years to be seen which can adversely affect a person's quality of life.

- The data obtained within this study recommends that within the medical sphere there is a need for increasing the number of Consultant Neurologists, Epilepsy Specialist Nurses, Educational Psychologists and Neuro-Psychologists. This increase of professionals in the field of epilepsy would be optimised by the development of epilepsy centres whereby all professionals would be accessible to patients, information would be available and support groups could be developed. It would allow for a multi-disciplinary approach for people with epilepsy and would allow greater communication between all allied health professionals dealing with people with epilepsy.

This study highlights the need for people with epilepsy to be more adequately informed in relation to all aspects of their epilepsy as one third of respondents felt inadequately informed.

- The findings of this study recommend professionals in the field of epilepsy need to address this issue in allowing more time with patients so that all aspects of their epilepsy are addressed. This may allow the empowerment of patients in taking responsibility for their condition and its management and therefore improving their quality of life.

8.6 Conclusion

This study has highlighted numerous issues for people with epilepsy living in the western region of Ireland. The clinical implications of epilepsy such as seizure frequency and medication are vital components in treating a person with epilepsy. However, the social and psychological implications of epilepsy are fundamental considerations which need to be given the same attention in dealing with people with epilepsy. The recommendations of this study are considered to be essential as they were developed through findings reported by people with epilepsy who were involved in each stage of the research process. However the main limitation within this research was the difficulty accessing participants. It should be noted that due to the absence of a national database regarding the number of people with epilepsy in Ireland. Therefore the researcher distributed questionnaires through the Brainwave database and has no way of knowing how representative the sample within this research was which leaves it difficult to generalise the findings. However, it is hoped that this research provides a valuable insight into quality of life issues of people with epilepsy living in the Western region of Ireland and may provide a valuable framework for future research.

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Appendix A – International League Against Epilepsy Seizure Classification

Generalised seizures – in this type, the entire brain is affected at onset. Consciousness is lost. There are six main types of generalised seizure;

- Absence - involves a brief loss of awareness, it may last between five and 20 seconds and can happen hundreds of times a day. This type of seizure usually starts in childhood and can be mistaken as daydreaming.
- Tonic – involves a general stiffening of muscles, it usually lasts about ten seconds and the person will fall so there is a risk of injury
- Atonic – involves a sudden loss of muscle tone, therefore causing a fall to the ground
- Myclonic – involves sudden jerking of the limbs. This can happen on its own or with other forms of generalised seizure and usually only lasts a few seconds.
- Tonic-clonic – involves a sudden overall contracting of all muscles, the person falls to the ground with jerking of all four limbs, breathing is laboured and consciousness is lost for anything up to three minutes. When the seizure stops the person may be tired, have painful muscles or a headache.

Partial Seizures – In this type of seizure only part of the brain is affected at onset, though it may spread throughout the whole brain. When this occurs it is called a secondary generalised seizure. The nature of these seizures is usually determined by the function of the part of the brain that is involved. There are two main types of partial seizures;

- Simple partial – involves unusual electrical activity taking place in parts of the brain that control seeing, hearing, memory and sensation. Although the person is conscious he/she is unable to control their movements. Depending on the individual they may hear strange sounds, surroundings may become distorted or unfamiliar or they may experience feelings of fear, dread or anger.

An 'aura' is the initial part of a simple partial seizure and usually consists of a strange feeling in the stomach, an unusual taste or smell or some other sensory disturbance. This aura can be a warning of a further seizure. If a partial seizure spreads to the areas of the brain concerned with consciousness then it becomes a complex partial seizure.

- Complex partial – involves the spreading of the electrical disturbance far enough over the brain so that the person is unaware of events while the seizure is occurring. Sometimes these happen without an 'aura'. The person appears in a trance and has no control over movements: which can consist of chewing, staring, pulling at clothes and looking confused. Awareness may not return for some time, even though the seizure only usually lasts for a minute or two.

Appendix B - Topic Guide

1) Impact seizure frequency had on your quality of life?

2) Misconceptions about epilepsy held by general public?

3) Implications of having epilepsy in relation to
   - Information given
   - Medical treatment
   - Health services
   - Anti-epileptic medication

4) Impact on quality of life with regard to
   - Social activities
   - Sport/leisure activities
   - Memory/concentration
   - Alcohol/sleep
   - Mood/general well-being
   - Employment
   - Driving restrictions

5) What would be considered most important to you in achieving best possible quality of life?

6) Any additional comments or areas you wish to highlight/discuss?

Appendix C - Exit Questionnaire

1) Date:

2) Age:

3) Relationship status:

4) What is the highest educational achievement you have received?
Primary level { }
Secondary level { }
Third level { }

5) How many years have you had epilepsy?.....years.

6) Explain what quality of life means to you?

7) Please indicate how your epilepsy affects your quality of life in relation to each of the following areas **(Please tick one box in each area)**

	Extremely	Quite a bit	Moderately	A little bit	Not at all
Social activities					
Sport/leisure activities					
Employment					
Driving					
Mood					
Memory					
Concentration					
Seizure frequency					

8) Is there anything else you would have included in the discussion?

9) Is there anything else you would like to add or any final comments?

Thank you for your time and participation

Appendix D – Questionnaire/Codebook

For office use only:

C	1			

Questionnaire

All information received will remain confidential. Thank you for taking the time to fill out this questionnaire.

Section 1 – General Questions

Code

Question 1
Gender

Male	{ }	1
Female	{ }	2

Question 2

Age

Under 20 yrs	{ }	1
20yrs - 29yrs	{ }	2
30yrs – 39yrs	{ }	3
40yrs – 49yrs	{ }	4
50yrs – 59yrs	{ }	5
60yrs or over	{ }	6

Question 3
Marital status

Single	{ }	1
Co-habiting	{ }	2
Married	{ }	3
Widowed	{ }	4
Divorced	{ }	5
Other	{ } Please specify_____	6

Section 2 – Health Questions

Question 4
How many years have you had epilepsy?.....years.

Question 5

(a) Is there a history of epilepsy in your family?

Yes	{ }	1
No	{ }	2
Don't know	{ }	3

(b) Please explain your answer further

_____

_____

_____

Question 6
Who carried out your initial assessment?

GP	{ }	1
Neurologist	{ }	2
Nurse	{ }	3
Other	{ } Please specify_____	4

Question 7

(a) When you were diagnosed with epilepsy were you offered support facilities?

Yes	{ }	1
No	{ }	2
Don't Know	{ }	3

(b) If **yes**, please state where you received support from?

Brainwave	{ }	1 2
Neurology services	{ }	1 2
Counselling	{ }	1 2
None	{ }	1 2
Other	{ } Please specify_____	1 2

Question 8

Have you been seen by a Consultant Neurologist?

Yes	{ }	1
No	{ }	2

Question 9

If so, how many months did you wait for an appointment?

Under 5 months	{ }	1
6 months – 1 year	{ }	2
13 months – 2 years	{ }	3
Over 2 years	{ }	4

Question 10

(a) Are you currently taking anti-epileptic medication?

Yes	{ }	1
No	{ }	2

(b) If **yes**, how many different types do you take?

One	{ }	1
Two	{ }	2
Three or more	{ }	3

(c) Does taking medication affect your quality of life?

Extremely	{ }	1
Quite a bit	{ }	2
Moderately	{ }	3
A little bit	{ }	4
Not at all	{ }	5

Please explain your answer further

_____

_____

_____

Question 11

Are your seizures usually

Controlled	{ }	1
Uncontrolled	{ }	2

Question 12

How frequent are your seizures?

Frequent (more than 1 a month)	{ }	1
Infrequent (less than 1 a month)	{ }	2
Seizure free (for over a year)	{ }	3

Question 13
How does your seizure frequency affect your quality of life?

_____

_____

_____

Question 14
Presently how would you rate your general health?

Excellent	{ }	1
Very good	{ }	2
Good	{ }	3
Fair	{ }	4
Poor	{ }	5

Question 15
Presently how would you rate your quality of life in relation to your health?

Excellent	{ }	1
Very good	{ }	2
Good	{ }	3
Fair	{ }	4
Poor	{ }	5

Please indicate your level of agreement with the statements below by circling your response: Strongly agree (SA), Agree (A), Undecided (U), Disagree (D) or Strongly disagree (SD)

My general health is excellent

SA	A	U	D	SD
1	2	3	4	5

I have received sufficient information in relation to all aspects of my epilepsy

SA	A	U	D	SD
1	2	3	4	5

The waiting times to see a consultant neurologist are too long

SA	A	U	D	SD
1	2	3	4	5

There are adequate support facilities for people with epilepsy

SA	A	U	D	SD
1	2	3	4	5

My overall quality of life is excellent

SA	A	U	D	SD
1	2	3	4	5

Section 3 – Social Questions

Question 16

What is the highest educational qualifications you have achieved?

Primary level	{ }	1
Secondary level	{ }	2
Third level	{ }	3
Other	{ } Please specify_____	4

Question 17

(a) What is your current employment status?

Employed (full or part time)	{ }	1
Unemployed	{ }	2
Self-employed	{ }	3
Retired	{ }	4
Homemaker	{ }	5
Student	{ }	6

(b) When employed have you disclosed your epilepsy to your employer?

Yes	{ }	1
No	{ }	2

(c) If **no**, please state your reasons for not disclosing your epilepsy?

_____

_____

_____

Question 18

Have you ever had an accident at work due to experiencing a seizure?

Yes	{ }	1
No	{ }	2

Question 19

Do you feel epilepsy has an affect on your employment prospects, please explain?

_____

_____

_____

Question 20

(a) Do you hold a drivers license?

Yes	{ }	1
No	{ }	2

(b) Are you currently certified to drive?

Yes	{ }	1
No	{ }	2

(c) If you are not certified to drive/do not hold a driver's license, how do you feel this impacts on your quality of life, please explain?

_____

_____

_____

Question 21

Do you feel your epilepsy has an impact on your social activities?
(such as visiting friends/family)

Yes	{ }	1
No	{ }	2
Don't know	{ }	3

Please explain your answer further

_____

_____

_____

Question 22

(a) Do you participate in sport/leisure activities regularly?

Yes	{ }	1
No	{ }	2

(b) Do you feel your epilepsy has an impact on your sport/leisure activities?

Yes	{ }	1
No	{ }	2
Don't know	{ }	3

Question 23
If you do not participate in sport/leisure activities please state reason?
(Please tick one box)

Time limits	{ }	1
Epilepsy itself	{ }	2
Fear of seizure	{ }	3
Lack of motivation	{ }	4
Advised not to	{ }	5
Other	{ }	6

Please explain your answer further

_____

_____

_____

Question 24

Have you experienced a seizure during sport/leisure activities?

Yes	{ }	1
No	{ }	2

Question 25

Do you feel you are sufficiently informed in relation to performing sports?

Yes	{ }	1
No	{ }	2
Don't know	{ }	3

Question 26
Presently how would you rate your quality of life in relation to your participation in all aspects of society?

Excellent	{ }	1
Very good	{ }	2
Good	{ }	3
Fair	{ }	4
Poor	{ }	5

Please indicate your level of agreement with the statements below by circling your response: Strongly agree (SA), Agree (A), Undecided (U), Disagree (D) or Strongly disagree (SD)

Seizure frequency has a negative impact on my quality of life

SA	A	U	D	SD
1	2	3	4	5

My epilepsy interferes with my social activities

SA	A	U	D	SD
1	2	3	4	5

Having epilepsy has a negative impact on employment prospects

SA	A	U	D	SD
1	2	3	4	5

Taking anti-epileptic medication interferes with my quality of life

SA	A	U	D	SD
1	2	3	4	5

Driving restrictions due to my epilepsy impact on my quality of life

SA	A	U	D	SD
1	2	3	4	5

Section 4 – General well-being Questions

Question 27

Do you feel your epilepsy has an affect on your memory?

Yes	{ }	1
No	{ }	2
Don't know	{ }	3

Please explain your answer further

_____

_____

_____

Question 28

(a) Do you worry about having a seizure?

Yes	{ }	1
No	{ }	2

(b) If **yes**, in what way does this worry affect your quality of life?

_____

_____

_____

Question 29

Do you worry about injuring yourself when you have a seizure?

Yes	{ }	1
No	{ }	2

Question 30

(a) What injuries have you had in the past year as a result of a seizure?

Burn/scald	{ }	1 2
Head injury	{ }	1 2
Cuts/bruises	{ }	1 2
Back pain	{ }	1 2
No injury	{ }	1 2
Other	{ } Please specify_____	1 2

(b) If you have had no injury in the past year, have you ever had an injury as a result of a seizure?

Yes	{ }	1
No	{ }	2
Don't know	{ }	3

Please explain your answer further

_____

_____

_____

Question 31

(a) Do you feel that the general public holds myths about epilepsy?

Yes	{ }	1
No	{ }	2

(b) If yes, please state what myths you feel the general public hold relating to epilepsy?

_____

_____

_____

(c) In your opinion, what can be done to ensure the public no longer hold myths, if any, relating to epilepsy?

_____

_____

_____

Question 32

(a) Do you drink alcohol?

Yes	{ }	1
No	{ }	2

(b) If yes, do you feel alcohol has an affect on your seizure frequency?

Yes	{ }	1
No	{ }	2
Don't know	{ }	3

(c) Please explain your answer further

_____

_____

_____

Question 33

(a) Do you feel that lack of sleep has an affect on your seizure frequency?

Yes	{ }	1
No	{ }	2
Don't know	{ }	3

(b) Please explain your answer further

_____

_____

_____

Question 34

(a) Do you feel that your epilepsy has an affect on your concentration?

Yes	{ }	1
No	{ }	2
Don't know	{ }	3

(b) Please explain your answer further

_____

_____

_____

Question 35

(a) Do you feel that your epilepsy has an affect on your mood?

Yes	{ }	1
No	{ }	2
Don't know	{ }	3

(b) Please explain your answer further

_____

_____

_____

Question 36

(a) In relation to your epilepsy which of the following would be the most important to you in achieving best possible quality of life? **(Please tick one box)**

Driving	{ }	1
Employment	{ }	2
Education	{ }	3
Independence	{ }	4
Safety	{ }	5
AED side effects	{ }	6
Seizure control	{ }	7
Other	{ }	8

(b) Please explain your answer further

_____

_____

_____

Question 37

Presently how would you rate your quality of life in relation to your overall well-being?

Excellent	{ }	1
Very good	{ }	2
Good	{ }	3
Fair	{ }	4
Poor	{ }	5

Please indicate your level of agreement with the statements below by circling your response: Strongly agree (SA), Agree (A), Undecided (U), Disagree (D) or Strongly disagree (SD)

I have felt discouraged by problems relating to my epilepsy

SA	A	U	D	SD
1	2	3	4	5

I do not worry about having seizures

SA	A	U	D	SD
1	2	3	4	5

My epilepsy does not affect my mood

SA	A	U	D	SD
1	2	3	4	5

Having epilepsy is a financial burden

SA	A	U	D	SD
1	2	3	4	5

My quality of life is excellent

SA	A	U	D	SD
1	2	3	4	5

Question 38
Define quality of life? (in three words)

_____

Question 39
Explain what quality of life means to you?

_____

_____

_____

Question 40
Is there anything else you would like to add, or any final comments?

_____

_____

_____

_____

_____

_____

Thank you for taking the time to complete this questionnaire, your participation will be vital to the success of the research.

Appendix E - Cover Letter

School of Business & Humanities
Institute of Technology
Sligo

To whom it may concern,

My name is Tracy Mc Govern. I am a postgraduate student in Sligo I.T and I am presently conducting a Research Masters. The research is based on exploring quality of life issues for adults with epilepsy living within the western region of Ireland.

I would appreciate if you could fill out the enclosed questionnaire, if you have epilepsy and are over 18. The aim of the research is to significantly increase our understanding of epilepsy while raising awareness of the key issues surrounding this condition in order to develop more adequate service provision.

All information received will remain confidential and completed questionnaires will be shredded when the research is finished. Stamped addressed envelopes have been enclosed for your convenience and I would greatly appreciate if you could return completed questionnaires as soon as possible.

Thank you for your much needed and essential participation. If you have any questions or if you wish to take part in a focus group please do not hesitate to contact me on 086 – 8946951.

Tracy Mc Govern

Appendix F - Guideline of Interview Questions (Professionals)

Professional background

Outline of profession

Question 1

a) In your opinion, what are the implications of epilepsy?

b) What are the main quality of life issues for people with epilepsy?

Question 2

a) Upon diagnosis what support services are offered to patients?

b) What information is given to patients in relation to their epilepsy?

Question 3

a) In your opinion, is there communication between health care professionals with regard to epilepsy i.e. GP, neurologist, A&E etc?

b) Are there barriers to the care of people with epilepsy?

Question 4

a) Are there effects of medication on the quality of life of people with epilepsy?

b) Are there other treatments besides medication that could be useful to control seizures?

Question 5

In your opinion is there a stigma attached to this condition?

Question 6

In your opinion, what are the most important unmet needs for people with epilepsy?

Question 7

Are there recommendations for future policies or strategies to overcome challenges in relation to epilepsy?

Question 8

Are there any additional comments or issues would like to add?

Appendix G - Interview Questions (People with epilepsy)

Physical/ health Questions

What age were you when you were diagnosed with epilepsy?

Have you seen a Consultant Neurologist?

How long did you wait fro an appointment?

Have you been given enough information about your epilepsy?

When you were diagnosed were you offered support facilities?

Do you take medication? If so, do you feel it affects your quality of life?

Have you side-effects from the medication?

Is your epilepsy controlled or uncontrolled?

How often do you have seizures?

Social Questions

Do you feel that the general public hold myths about epilepsy?

In what ways could the general public be more informed about epilepsy?

Do you feel your epilepsy has an affect on your employment prospects?

Would you disclose your epilepsy to an employer and why?

Does your epilepsy affect relationships with family and friends?

Does your epilepsy affect your quality of life?

Psychological/ General Well-being Questions

Do you worry about your epilepsy, having seizures or injuring yourself?

How does this worry affect your quality of life?

How did you adjust to the diagnosis of epilepsy?

Is there a stigma attached to this condition?

In your opinion, what are the most important unmet needs for people with epilepsy?

Are there specific quality of life issues for you?

Additional comments?

Appendix H – Consent Form

I volunteer to participate in this focus group where information obtained will be used in the writing up of my thesis with the possibility of presentation and publication. However, individuals' identities will remain confidential.

_____

Date:_____

Appendix I - Quantitative Data Analysis (Sample)

How frequent are your seizures? * Are your seizures usually Crosstabulation

			Are your seizures usually		Total
			Controlled	Uncontrolled	Controlled
How frequent are your seizures?	Frequent (more than 1 a month)	Count	10	17	27
		% within Are your seizures usually	12.8%	70.8%	26.5%
	Infrequent (less than 1 a month)	Count	17	3	20
		% within Are your seizures usually	21.8%	12.5%	19.6%
	Seizure free (for over a year)	Count	51	4	55
		% within Are your seizures usually	65.4%	16.7%	53.9%
Total		Count	78	24	102
		% within Are your seizures usually	100.0%	100.0%	100.0%

How frequent are your seizures? * Do you worry about injuring yourself when you have a seizure? Crosstabulation

			Do you worry about injuring yourself when you have a seizure?		Total
			Yes	No	Yes
How frequent are your seizures?	Frequent (more than 1 a month)	Count	18	10	28
		% within How frequent are your seizures?	64.3%	35.7%	100.0%
	Infrequent (less than 1 a month)	Count	16	5	21
		% within How frequent are your seizures?	76.2%	23.8%	100.0%
	Seizure free (for over a year)	Count	28	30	58
		% within How frequent are your seizures?	48.3%	51.7%	100.0%
Total		Count	62	45	107
		% within How frequent are your seizures?	57.9%	42.1%	100.0%

What is your current employment status? * How frequent are your seizures? Crosstabulation

			How frequent are your seizures?			Total
			Frequent (more than 1 a month)	Infrequent (less than 1 a month)	Seizure free (for over a year)	Frequent (more than 1 a month)
What is your current employment status?	Employed (full or part time)	Count	9	10	26	45
		% within What is your current employment status?	20.0%	22.2%	57.8%	100.0%
		% within How frequent are your seizures?	**45.0%**	**52.6%**	**66.7%**	57.7%
	Unemployed	Count	11	7	9	27
		% within What is your current employment status?	40.7%	25.9%	33.3%	100.0%
		% within How frequent are your seizures?	**55.0%**	**36.8%**	**23.1%**	34.6%
	Self-employed	Count	0	2	4	6
		% within What is your current employment status?	.0%	33.3%	66.7%	100.0%
		% within How frequent are your seizures?	**.0%**	**10.5%**	**10.3%**	7.7%
Total		Count	20	19	39	78
		% within What is your current employment status?	25.6%	24.4%	50.0%	100.0%
		% within How frequent are your seizures?	**100.0%**	**100.0%**	**100.0%**	100.0%

Do you feel you are sufficiently informed in relation to performing sports? * Do you feel your epilepsy has an impact on your sport-leisure activities? Crosstabulation

			Do you feel your epilepsy has an impact on your sport-leisure activities?			Total
			Yes	No	Don't Know	Yes
Do you feel you are sufficiently informed in relation to performing sports?	Yes	Count	12	21	3	36
		% within Do you feel you are sufficiently informed in relation to performing sports?	33.3%	58.3%	8.3%	100.0%
		% within Do you feel your epilepsy has an impact on your sport-leisure activities?	30.0%	42.9%	33.3%	36.7%
	No	Count	21	14	1	36
		% within Do you feel you are sufficiently informed in relation to performing sports?	**58.3%**	38.9%	2.8%	100.0%
		% within Do you feel your epilepsy has an impact on your sport-leisure activities?	52.5%	28.6%	11.1%	36.7%
	Don't Know	Count	7	14	5	26
		% within Do you feel you are sufficiently informed in relation to performing sports?	26.9%	53.8%	19.2%	100.0%
		% within Do you feel your epilepsy has an impact on your sport-leisure activities?	17.5%	28.6%	55.6%	26.5%
Total		Count	40	49	9	98
		% within Do you feel you are sufficiently informed in relation to performing sports?	40.8%	50.0%	9.2%	100.0%
		% within Do you feel your epilepsy has an impact on your sport-leisure activities?	100.0%	100.0%	100.0%	100.0%

Gender * Are your seizures usually Crosstabulation

			Are your seizures usually		Total
			Controlled	Uncontrolled	Controlled
Gender	Male	Count	38	12	50
		% within Are your seizures usually	48.1%	50.0%	48.5%
	Female	Count	41	12	53
		% within Are your seizures usually	51.9%	50.0%	51.5%
Total		Count	79	24	103
		% within Are your seizures usually	100.0%	100.0%	100.0%

Appendix J – Excerpts from interviews with professionals and people with epilepsy (Sample)

Professionals

Consultant Neurologist

In your opinion, what are the implications of epilepsy?

Apart from the physical perils of having a seizure there's the embarrassment of it, when you realise what's happened and especially in the teenage years but also at any age. So it can lead to a secondary, a well described, secondary social phobia, where people with epilepsy stop going out so they increase their social isolation.

Anyway you have to be 12months seizure free and that's the law of the land otherwise you cannot legally drive and this is the hardest thing we have to tell patients with epilepsy very often and this obviously effects their quality of life, if you have to drive to work of if you have to drive your children to school or whatever it is, so this is a major issue.

Community Resource Officer 2

In your opinion, is there a stigma attached to this condition?

Even yesterday someone rang me, she lives in … and her brother lives in … and he'd been working, I won't mention the name, for a hospital right as a porter or something, he developed epilepsy and his employer who was a hospital told him that he couldn't possibly work if he had epilepsy because he would be working with the public, I mean can you believe that in this day and age, you would think you'd have some chance working in a medical environment either try and find out, like who are they trying to protect? So I'm afraid there is still a lot of stigma out there

Educator

In your experience, are there specific issues which frequently arise for people with epilepsy?

I suppose again for the student group the memory thing is huge because it is quite difficult if your short-term memory is badly affected, it is quite difficult to learn new things and with a lot of the people I work with either the medication is affecting their short-term memory or the particular type of epilepsy they have is having an effect on their memory.

They have its not unknown for people to wait a year or a year and a half for an appointment and that's bad enough but it's very frightening for somebody if their seizures are changing and their not sure why or what's going on they can be very insecure and vulnerable so that is difficult

People with Epilepsy

Interview with P1

Do you feel your epilepsy has an effect on your employment prospects?

Well when I started first working in my teens I applied for a job I was turned down, you know they were chatting away to me in the interview, when I told them I had epilepsy and you know that hurt, that hurt me big-time because you know when you go in for a job you think this is great you know so they wouldn't take, once I told them I had epilepsy no it was no good.

Have you been advised not to participate in sport/leisure activities or is that your decision?

Mammy recommended not to, like I used to go cycling when I was young but then mam said ….. no because when I get dizzy now you know get a warning she says no …. that's not good you know so I have a bike and its lying in the shed and I've only been on it three times its just lying there you know things like that and even like discos I don't go to them because the lights, I should have been a nun.

Interview with P4

Have you been seen by a Consultant Neurologist?

Now at the time when I was diagnosed they thought it was full blown tonic-clonic epilepsy that I had but it has since been found out that its actually a form called pseudo epilepsy which the best way to describe it is that its all kind of psychologically based.

How long did you wait for an appointment?

I actually didn't see a neurologist until I was nearly nineteen up until, what happened was my paediatrician at the time who was about to finish off with me diagnosed it. So what he decided to do was because the waiting list is so long and I could be waiting forever to see a neurologist and there was so few of them in the west of Ireland that he'd keep me on his patient list rather than hand me over to the adult section just until I was eighteen, so by then I should have been able to get a neurologist appointment.