Athlone Institute of Technology

Epilepsy, a hidden disability:

An exploration of epilepsy and the possible challenges and supports which young adults encounter, during their academic journey.

Gillian Mc Ardle

Submitted in part fulfilment of the Master of Arts in Child and Youth Care

27th/May/2016

Word count: 17,541

“I have a ‘friend’,

This ‘friend’ is invisible and follows me everywhere I go but refuses to leave, even when I am at home. This ‘friend’ is epilepsy. I don’t care much for this ‘friend’, though I have known it all my life. It is not kind. It attacks with violence or silence however the mood strikes but always without warning. My ‘friend causes injuries to my body, tears to my mind, steals my memories but leaves me broken and bruised. My ‘friend separates and isolates me from the ‘normal reality’ of world, where nobody can see it, ‘Epilepsy my friend is hidden, but is always with me”.

(Browne, 2011, p183)

SIGNED DECLARATION

I declare that this dissertation is a presentation of my original research work and the research involved in it are entirely the work of the author. This work, or part of it, has not been submitted for a qualification to any other institute or university.

All work was done under the direction of supervisor lecturer Ms. Pearl Moore at Athlone Institute of Technology, Dublin Road, Athlone, County Westmeath.

Signature: ___________________ Date: ______________________

ACKNOWLEDGEMENTS

Following the signed declaration, I firstly want to express my sincere appreciation to my supervisor Ms. Pearl Moore for the continuous support she has demonstrated throughout my five years within Athlone Institute of Technology and through my M.A in Child and Youth Studies which is related to this research. Her support, direction, vast knowledge, patience and motivation has been amazing through the duration of this research process. Her guidance has been hugely influential both on my academic journey and as well as bringing this dissertation to completion. I could not imagine having a better supervisor to assist me in my Master's in Child and Youth.

Secondly, to the officers and staff within the disability section at Athlone I.T, to all the lectures who have educated me and Goldsmiths library staff for their assistance. All their expertise, experience, support and guidance will always be remembered and appreciated on my future journey.

Thirdly, this dissertation would not have been possible without the patience and support from the course manager of the facility where the research was carried out, Mrs Honor Broderick, she always believed that this dissertation was worthwhile and encouraged me during times of doubt. Honor acted as a gate-keeper by recruiting participants for the study. Alongside Honor, Maire Tansey also contributed greatly. Without their support this study would not have come to fruition. Thank you both.

Fourthly, my heartfelt thanks goes out to the seven men and three women who participated in the research. Hearing their personal experiences and views on the education environment has enlightened my own discernment and may influence further studies to be carried out. For this I am eternally grateful.

Finally, I want to acknowledge the influence of my family and close friends. Their patience, help and support, including their constant motivation and encouragement made it possible to bring this dissertation to a completion.

TABLE OF CONTENTS

SIGNED DECLARATION i

ACKNOWLEDGEMENTS ii

LIST OF TABLES v

GLOSSARY vi

LIST OF ABBREVIATIONS vii

ABSTRACT ix

1. LITERATURE REVIEW .... - 1 -

1.1 The ‘word’ Epilepsy .... - 1 -

1.2 Epilepsy and its prevalence .... - 2 -

1.3 Personal experience of initial diagnosis .... - 2 -

1.4 Medication prescribed for epilepsy and education .... - 2 -

1.5 Epilepsy, education needs and available support .... - 3 -

1.6 Potential barriers and main challenges .... - 6 -

1.7 Epilepsy and family adjustment .... - 8 -

1.8 Public perceptions and attitudes of society towards .... - 8 -

1.9 Coping strategies .... - 9 -

1.10 Important supports that should be available .... - 9 -

Conclusion .... - 10 -

2. METHODOLOGY .... - 11 -

2.1 Research Design .... - 11 -

2.2 Recruitment of Participants .... - 13 -

2.3 A profile of participants .... - 14 -

2.4 Research Materials .... - 15 -

2.5 Procedure .... - 15 -

2.6 Ethical Considerations .... - 18 -

2.7 Thematic Analysis .... - 19 -

2.8 Delimitations of the Study .... - 20 -

Conclusion .... - 21 -

3. Results .... - 22 -

3.1 Section One findings .... - 22 -

3.1 (a) Personal experience of initial diagnosis .... - 23 -

i. ***Theme One:*** *Surprise and upsetting emotions* .... - 24 -

ii. ***Theme Two:*** *Career Change* .... - 24 -
iii. ***Theme Three:*** *Memory* .... - 25 -
iv. ***Theme Four:*** *Eye sight and concentration levels* .... - 26 -
3.1 (b) Educational supports available .... - 27 -
i. ***Theme One:*** *Understanding and knowledge of Epilepsy in schools* .... - 27 -
ii. ***Theme Two:*** *Academic support available in national and secondary level* - 28 -
iii. ***Theme Three:*** *Academic Supports Available in Third level* .... - 30 -
3.2 Section Two findings .... - 31 -
3.2 (a) Potential barriers .... - 31 -
i. ***Theme One:*** *Friendships* .... - 32 -
ii. ***Theme Two:*** *Side effects to medication* .... - 33 -
iii. ***Theme Three:*** *Social Isolation and restriction* .... - 33 -
3.2 (b) Main challenges .... - 34 -
i. ***Theme One:*** *Fear of a seizure* .... - 34 -
ii. ***Theme Two:*** *Social Life* .... - 34 -
iii. ***Theme Three:*** *Stigma* .... - 34 -
3.2 (c) Coping strategies .... - 35 -
i. ***Theme Two:*** *Knowledge of triggers* .... - 35 -
iii. ***Theme Three:*** *Realisation* .... - 36 -
3.2 (d) Important supports that should be available. .... - 36 -
i. ***Theme One:*** *Suggested Supports* .... - 37 -
ii. ***Theme Two:*** *Lack of Mental Health supports available* .... - 37 -
Conclusion .... - 38 -
4. DISCUSSION .... - 39 -
4.2 Personal experience of initial diagnosis .... - 39 -
4.3 Medication prescribed for epilepsy affect education .... - 40 -
4.4 Are educational supports available? .... - 41 -
4.5 Potential barriers faced and challenges within the educational environment- 48 -
4.6 Coping strategies .... - 51 -
4.7 Important supports that should be available .... - 52 -
4.8 Evaluation of Method and Suggestion for future Research .... - 52 -
Summary .... - 53 -
5. CONCLUSION .... - 54 -

6. RECOMMENDATIONS ....- 56 -
7. REFERENCE LIST ....- 58 -
8. APPENDICES ....- 68 -
APPENDIX 1: Letter to head of school, Business & Social Sciences..................- 68 -
APPENDIX 2: Letter to ‘Training for Success’ programme, course manager.......- 69 -
APPENDIX 3: Letter of response, approving the research..................................- 70 -
APPENDIX 4: Information sheet ....- 71 -
APPENDIX 6: List of interview questions ....- 74 -
APPENDIX 7: Interview schedule ....- 75 -
APPENDIX 8: Information leaflet of services available..- 76 -
APPENDIX 9: Classification and different types of epilepsy................................- 77 -
APPENDIX 10: First Aid for Epilepsy/Complex partial seizures ....- 80 -
APPENDIX 11: First Aid for Epilepsy/Tonic Clonic seizures ....- 81 -
APPENDIX 12: Files which should be in each school worldwide - awareness of my seizure plan...- 82 -
APPENDIX 13: 2010 summary of driving regulations in respect of epilepsy........- 83 -
APPENDIX 14: Epilepsy and its’ hidden consequences.......................................- 86 -

LIST OF TABLES

Table 1 – Profile of Participants' ....- 14 -
Table 2 – Different types of Seizures ....- 22 -
Table 3 – Section One – Objective One – Headings and Themes......................- 23 -
Table 4 – Section Two – Objective Two – Headings and Themes......................- 31 -

GLOSSARY

Seizures fall into two categories: ***1) Focal/partial seizures*** *and* ***2) Primary/Secondary Generalised seizures*** The difference between these types is how they begin.
1) Partial Seizures
Simple Partial – The person is aware during the seizure and only occurs in one part of the brain. It can involve motor, sensory, psychic or autonomic symptoms.
Complex Partial – The person experiences altered awareness and it only occurs in one part of the brain. People may appear confused and dazed.
It is important to recognise that both simple partial and complex partial seizures may develop into secondary generalised seizures.
2) Generalized Seizures
Tonic Clonic seizures 'Grand mal' – Occurs in two stages, 1) *Tonic phase,* typically involves a groan or crying, loss of awareness and a fall as consciousness is lost and muscles stiffen, lasting about 10 to 20 seconds. 2) *Clonic phase*, typically involves jerking, twitching and convulsion, of all four limbs, lasting for less than two minutes.
Atonic seizures – A sudden loss of muscle tone that can result in a dropping of objects, a person falling or nodding the head involuntarily.
Myoclonic – Results in sudden jerks of parts of the body, such as the legs or arms. The person may fall down.
Absence 'Petit mal' – A person's awareness is impaired during the seizure. It starts and ends abruptly, resulting in a blank stare, lasting less than 10 seconds.

**Refer to appendices 9, 10 & 11 for an in-depth description on each seizure type and the first aid required.*

LIST OF ABBREVIATIONS

AED	Anti-epileptic drug
CBT	Cognitive Behavioural Therapy
EAGCE	Expert Advisory Group on Certificate Examinations
G.P	General Practitioner
ILAE	International league against epilepsy
JCEB	Joint Council of Examination Boards
NCCA	National Council for Curriculum and Assessment
OCD	Obsessive Compulsive Disorder
PWE	People with epilepsy
SERC	Special Education Review Committee
SNA’s	Special Needs Assistants
YP	Young people
YPWE	Young people with epilepsy

Abstract

ABSTRACT

One out of three young people living with epilepsy expect their lives to be negatively impacted in the future and are specifically anxious about education, travelling, exploring and employment opportunities (Jacoby and Baker 2008). The aim of this study is create an awareness about epilepsy and to investigate the possible challenges faced by young adults with epilepsy, during their academic journey.

AIMS: The objective of the study is to gain an insight into young people's personal experience of initial diagnosis and the educational supports available. It will also explore the potential barriers faced by these young adults within their educational environment, whilst also examining their relevant coping strategies.

METHOD: Thematic analysis was used to analyse semi-structured one-to-one interviews with ten participants. Each participant had daily experiences of epilepsy, as a 'hidden' disability and the interview questions focussed on the personal experiences and attitudes of participants in relation to their individual academic journeys.

RESULTS: The main findings suggest that while there are some supports available in the educational system, there remains significant concerns about educating young adults with epilepsy in a mainstream setting. In particular, results suggested the fact that Ireland is the only country in the EU not to recognise the need for special educational or assessment facilities for people with epilepsy is a major barrier to greater educational attainment within an epilepsy population.

CONCLUSIONS: Findings indicate that all Government bodies, educators, teacher unions and parents need to make significant changes to ensure more supports are available in educational environments for individuals with epilepsy.

Chapter One

Literature Review

1. LITERATURE REVIEW

> *"Epilepsy, as a hidden disability, within schools may be defined, as a need to reform and review the educational structures, curriculum, arrangements and policies so that all individuals with a disability can receive adequate and equal opportunities to learn appropriately and positively".*
>
> (Bishop and Boag, 2006 p.401).

This research will aim to create an awareness about epilepsy and to investigate the possible challenges faced by young adults with epilepsy during their academic journey. Firstly, the research seeks to gain an insight into the personal experience of initial diagnosis and the educational supports available. Secondly, the research seeks to document and analyse the potential barriers faced by these young adults within their educational environment; and to examine their relevant coping strategies.

Objective One: To gain an insight into their personal experience of initial diagnosis and the educational supports available.

1.1 The 'word' Epilepsy

The word 'The Epilepsies', suggest there is no single disease of 'epilepsy'. (O' Donohue, 1994). 'Epilepsy' is derived from the Greek, meaning 'to be seized or to be beleaguered by surprise' (Frieden, 2010). Epilepsy is an unremitting neurological disorder which affects both males and females of all ages worldwide. Mc Govern (1995) stated that medically, an individual with epilepsy is a person who is subject to persistent interruptions in relation to brain function as a result of abrupt, uncontrollable nerve cell discharge. However, Mc Govern adds that epilepsy is not a 'nervous' condition in the more commonly accepted sense of the word. The occurrence of two or more unprovoked seizures within a 24 hour period has been traditionally defined as epilepsy (Sillanpaa, Johanssen, Blennow & Dam, (1990), cited in Egg-Olofsson). Fisher, (2005), stated that tendency of having seizures varies from person to person and depends on a number of things; for the majority, epilepsy will only affect them for a short period of their lives.

1.2 Epilepsy and its prevalence

Worldwide roughly 50 million people have epilepsy, with one of 21 men and one of 28 women developing epilepsy during their lifetime (Joint Epilepsy Council, 2011).There are between 30,000 and 40,000 people with epilepsy in Ireland at present (Epilepsy Ireland, 2010). In particular, Epilepsy Ireland (2010) estimate that around one-third of those living with epilepsy, may never seek medical advice for symptoms, so an exact measure of prevalence is especially difficult to establish.

1.3 Personal experience of initial diagnosis

Sillanpaa (1992) suggests that gaining a definite diagnosis is important, without delay, but an accurate diagnosis can take time. There are many different types of seizures and a person may have more than one type, but the pattern of seizures tend to remain relatively constant. Seizures are known as 'Partial', or 'Generalized', and each effects the brain in distinct ways. Generalized seizures typically affects the whole brain while 'Partial' only affect the part of the brain which involved in the seizure (Brainwave, cited in: information booklet, 1992) A study carried out in secondary education school on 11- 16 year olds by Reynolds and Trimble (1981) cited in O'Donohoue (1994) found that 65% of individual had complex partial, 3% photosensitive and 32% tonic clonic seizures were the most common *(Refer to Glossary and Appendix for more information)*

1.4 Medication prescribed for epilepsy and education

It has been demonstrated that adherence to medication can be a significant difficulty for those living with epilepsy (Reynolds & Trimble 1981). It has been suggested that this, in part, is associated with poor communication about the type and the long term effects of medication prescribed. Studies by De Boer (1995) have shown that communication regarding medication can be frequently inadequate and in particular that side effects were not sufficiently explained. They found that 27% did not know reasons to why they were prescribed a particular medicine, 27% felt their neurologist did not explain the individual medication prescribed and 38% reported that the side effects of treatment were never discussed. This study suggests that many patients do not believe they are receiving adequate information regarding treatment and are unaware of the long term effects of medication. De Boer (1995) recommends that when a diagnosis of epilepsy is given, there must be clear and consistent information communicated in a transparent and collaborative way, in order for patients to make informed decisions regarding care.

1.5 Epilepsy, education needs and available support

A review of education and epilepsy, Chung (1995), states that the misconceptions regarding the role of epilepsy in education are plentiful. He stresses that the conflicting assumptions, that epilepsy seldom affects school performance or that epilepsy has a major effect on education, are equally misleading.

There is evidence that epilepsy can impede the individual's ability to learn. Reynolds and Trimble (1981) cited in O'Donohoue (1994), claim that people commonly report problems with their memory and thinking, medication adherence, remembering names and short term recalls, although longer term memory typically remains unaffected. It has been shown that people with epilepsy find it difficult to concentrate or pay attention for long periods, and that they also report feeling that their thinking has slowed down (Reynolds and Trimble, 1981; cited in O'Donohoue, 1994).

The majority of individuals with epilepsy have their seizures under control and are attending mainstream education. However for those whose epilepsy is not under control through effective medication, achieving satisfactory educational attainment can be a significant challenge. Although a large amount of people with epilepsy do not encounter educational difficulties, studies of people who suffer recurrent seizures, do experience educational difficulties. Sillanpaa and Finland (1992) conducted a large study on epilepsy within schools on young adults, aged 4- 17 years. 143 individuals with epilepsy from a population of 21,104 were examined. The most frequent neurological impairments were speech disorder (28%), mental retardation (31%) and specific learning disabilities (23%), in people with epilepsy compared with controls. In earlier studies, Sillanpaa, (1983, 1990) concluded that 28% of young adults with epilepsy did not complete their basic education or required extra academic supports. This special educational provision is well established for young adults, however typically is designed for individuals with other learning disabilities and rarely caters for epilepsy related educational needs specifically.

A report from the Special Education Review Committee (SERC, 1993) has defined students with special needs as including "all those whose disabilities and/or circumstances prevent or hinder them from benefiting adequately from the education, which is normally provided for pupils of the same age, or for whom the education which can generally be provided in the ordinary classroom is not sufficiently challenging". Epilepsy Ireland aims to encourage the education of young people in mainstream education; however it also recognises the need for special schooling for those who have severe epilepsy or drug-resistance.

The minister for education established the National Council for Curriculum and Assessment (NCCA). Its purpose was to review matters in relation to assessment procedures and curriculum for both primary and secondary schools. The Education Act (1998) provides legislation established by the NCCA as a statutory body. The Education Act states that one function of the NCCA is "to advise the minister on the requirements, as regards curriculum and syllabuses, of students with disability or other special educational needs". The NCCA took into account findings from the SERC report (1993). However, epilepsy had not been defined or even included in the SERC report as an area which required special educational needs.

The Joint Council of Examination Boards (JCEB) (2008) may be able to help, or offer advice, where seizures are uncontrolled and are believed likely to affect a student around exam time. The JCEB stated that recognising concerns surrounding the school work or exam performance of an individual with epilepsy is vital in determining whether additional education support is required. Nevertheless, previous studies undertaken by Besag, (1995) showed that only two existing provisions (i.e. take the exam or miss it if a seizure occurs) in Ireland are made by the Department of Education and Science for students facing state exams. At present in Ireland, the same two existing provisions are identical to previous years, and these have not been updated to reflect a broader range of educational needs or requirements. Not all schools take these provisions into consideration and therefore do not provide for them (Epilepsy Ireland, 1998). Fastenau and Shen, (2008) produced evidence which suggest that individuals who have temporal lobe epilepsy find it more difficult to remember verbal materials than other types of materials. For students who are more likely to have seizures at a certain time of day or during times of stress, examinations may require particular consideration. In Ireland, the Department of Education and Science has allowance in place in third level education for students with special learning requirements which allows flexibility on an individual education attainment.

According to literature, there appears to be many different factors at play when it comes to the causation of educational difficulties in people with epilepsy. Determining the cause of educational difficulties and intervening to minimise/prevent any disadvantages to the individual are major factors in the management of people with epilepsy, who are having difficulties in school.

Anderson, Klassen, and Georgiou, (2007) undertook a study of perceptions of epilepsy among young people and teachers in mainstream education in Staffordshire, UK. While results showed more positive findings regarding teachers perceptions than those found by Ross and Tookey (1998), only 4% of teachers stated they felt ‘very confident’ when dealing with people and epilepsy, 33% felt ‘quite confident’ and 66% stated they ‘did not feel confident’. Teachers who had previously witnessed an individual having a seizure had higher confidence, and similarly those who had friends or relations with epilepsy felt they knew more about the condition. However the remaining 6% were not sure and stated they could do with further training. The educational establishment has a clear role in health services by ensuring that teachers have sufficient knowledge and the required support. Epilepsy Ireland (2010) states that in order to achieve optimal care, academics responsible for the education of those with epilepsy (even in mainstream education) must feel confident with the condition.

In a study of attitudes of teachers towards young people with epilepsy, Hani (1996) found that although teachers play a significant role in an individual’s life, they, may shelter misconceptions about epilepsy due to the absence of adequate instruction in their training courses. Unnecessary restrictions might possibly be placed on an individual, recreational or other school activities might be curtailed on the assumption they are harmful, or lower expectations of the individual might be set. Although this is often well meaning, it can contribute to an individual losing confidence and to an overall underachievement. Another study conducted on prescribed medication within schools by Besag (1998) showed that not all schools had a teacher trained in the area to administer medications such as ‘Rectal Diazepam’ or ‘Buccal Midazolam’. A designated person is required to administer medication and some teachers’ comments from the study regrettably are ‘*oh terrified of seizures or unable to cope with people who have them frequently*’, ‘*I would not be trained, I would call the parents’*, ‘*I didn’t realise such a drug had to be administered*’. If a seizure occurs or tends to occur in ‘clusters’, schooling for both the individual and the people within the classroom will become disrupted for a period of time. Pond, (1991) advises having substantial interventions and supports in place, may lessen the disturbance.

Epilepsy may not be the only contributory factor of the individual’s educational difficulties, however it is important to view these difficulties in a wide context (Besag, 1995). Conversely, epilepsy has proven to contribute to poor school attendance, where the individual is absent due to recurrent seizures or often sent home after a seizure. Epilepsy Ireland (2010) state when the adequate academic supports are not available for the individual to draw level then the Department of Education and Science needs to amend policies to ensure individuals with epilepsy reach the necessary educational achievement as those of the same age category.

Objective Two: To document and analyse the potential barriers faced by these young adults within their educational environment; and to examine their relevant coping strategies.

During adolescence biological changes take place which affect emotional, mental, and physical development. For young people with epilepsy, the ‘normal’ needs and concerns associated with adolescence are complicated by the demands of their condition. A key characteristic of epilepsy is its unpredictability (Zaslow and Takanishi, 1993).

1.6 Potential barriers and main challenges

Baker (1997) suggests that epilepsy related disadvantage stems from misconception and misunderstanding that still surrounds epilepsy. The reasons for this are often rooted deep in history. For many individuals with epilepsy, coping with the stigma surrounding epilepsy is often more difficult than living with restrictions imposed by the seizures or their treatment (Commission for the Control of Epilepsy and its Consequences, 1978). Barker, Buck, Jacoby, Monnet and Stalgis (1997), undertook a study on the quality of life of individuals with epilepsy in fifty European countries. They later reported over 50% felt stigmatised as a result of their epilepsy. Cevennes’s and Gallup (1998), found that approximately 44% of respondents were of the belief that many, but not everyone they had contact with, viewed them as different. Saraceno, (2005) suggests isolation in education and society may occur as a result of epilepsy. This, alongside the social reaction to the condition and the varying severity of clinical symptoms can significantly impact the quality of life for individuals. Epilepsy Ireland in 1998, at an awareness day, noted that many people attending had experienced discrimination because of their epilepsy.

People with epilepsy are often teased or bullied after a seizure. Baker (1997) suggests that stigma was still a major factor affected young adults living with epilepsy, and that this can be as challenging to cope with as the physical restriction imposed by the condition. Wong and Wirral (2006) believe the psychological damage caused by unnecessary stress and restrictions contribute to feelings of being inadequate and different for the individual with epilepsy. Rutter, Graham and Yule, (1971) states it is significant when people with epilepsy do participate in school activities, that teachers and parents provide encouragement in order to avoid restricting the activities.

Individuals with epilepsy face the same potential barriers daily as everyone else. They should be accompanied during activities such as cycling, horse riding or swimming by someone who is familiar with their condition and knows how to act should a seizure occur. Water sports such as canoeing, wind surfing and sailing carry a high degree of risk (Kean, 2004).

Once diagnosed, legal stipulations do not allow an individual to drive until they have experienced at least one year seizure free (Road safety authority, 2010). This can be barrier for many individuals, especially as their peers begin to drive. It can further restrict access to social contexts and can lead to increased isolation. Fenwick, (1996), found many people felt they lost a sense of independence and freedom when it came to learning to drive, because of their epilepsy. He found individuals, viewed driving as mark of independence and a rite of passage to adulthood. The severity or type of epilepsy a person has can determine whether or not they will receive a driving licence. If a person has nocturnal seizures (during their sleep) a driving licence may not be issued (Fenwick, 1996). Research indicates that people with epilepsy have the same driving accident rate as the average driver, however they do have a higher rate of crashes which involve injury. Drivers with epilepsy are also involved in more driving accidents that lead to fatality (Fenwick, 2014).

1.7 Epilepsy and family adjustment

Pond (1981) stated, ‘Overprotection’ is a response often given to the diagnosis of epilepsy. Beech (1992) carried out research on a group of third level students who were diagnosed with childhood epilepsy, which found that although 22% ‘felt completely independent with their own condition’, and 27% ‘felt just independent but would still have family support’, 51% ‘felt they dependent completely on their families for all aspects if their medical condition. Wallace (1994), states the majority of parents fear the consequences of allowing a child with epilepsy to increase their independence, and that this anxiety can only be reduced with increased education around the condition and recommends counselling. Previous studies by Mc Govern, (1992) showed that instead of overprotection or denial, parents are more concerned of the immediate reaction to the young adult which may be in various forms be rejection. Results from the study showed, this rejection maybe temporary or permanent; the individual may also be seen as someone who is ‘delicate’ or ‘second best’ and in need of special care, which in turn leads to family members placing restrictions on the individual (Rutter et.al. 1971).

Ward and Bower (1987) state that establishing a degree of understanding and awareness of epilepsy in society is necessary in order to increase the chances of eliminating discrimination. Ward and Bower (1987) have suggested that because people with epilepsy are often over-protected, it can limit the ability for individuals with medical condition to learn about fully about the condition, and to seek out what supports are available within the education system, which can have long term consequences for the ability to access help and navigate key social adjustments across their lives more generally.

1.8 Public perceptions and attitudes of society towards

Bauman, Wiese and Wilson (1995) carried out a telephone survey in America which found that 24% of participants foresaw a decline in the classroom environment if an individual with epilepsy was admitted. Bagel, (1972) conducted a survey on 2,610 participants, aging from 15 years to 19 years about the understanding, attitudes and public awareness towards individuals with epilepsy, it found 87% had heard of epilepsy, 70% knew people who had epilepsy and 56% had seen a seizure, however 18% objected to having their children associated with individuals who had epilepsy, may it be at play or in school. These negative attitude were associated with older teachers and the male population.

1.9 Coping strategies

Mc Govern, (1995), produced evidence that showed how feeling in control of the conditions was an important factor for individuals with epilepsy. This showed that for people with epilepsy, the unpredictable nature of the condition, especially when exposed to an environment in which a person can find it difficult to cope, can in fact trigger a seizure. It showed environments such as intense fear, mental or physical overstrain and rage or pain may be capable of triggering seizures in an individuals with epilepsy. Jacoby (1996) demonstrated that worrying or any type of stress, such as the prospects of a move to a new school or house, anxiety surrounding exams, or illness of parents can have the same effect. Medical influences such as dental treatments, blood tests and minor surgical operations can also trigger seizures (Jacoby, 1996). Individuals differ in that what trigger a seizures for one person, may not for the next person. Brainwave stated in their information booklet ‘Questions and Answers (1992) that approximately 5% of those who have epilepsy are photosensitive and could have a seizure as a result of flashing lights, such as sunlight through trees or strobe lights. Other known factors include exhaustion, lack of sleep or food, boredom, anxiety, excess alcohol, emotional stress, abrupt termination of anti-epileptic medication and in photosensitive epilepsy in particular, very regular or shimmering light patterns. Later studies were conducted by Mc Govern, (1995), to seek how individuals cope with what triggers a seizure on a daily basis. 67.7% ‘know what the triggers are and avoid these, 43.1% ‘Management of medication and diet’, 23.1% ‘Ensuring to get adequate sleep’, 13.8% ‘Music and light sports’ and 12.3% stated communicating on-line, if personal groups were accessible this would be beneficial’.

1.10 Important supports that should be available

Research reported from Epilepsy Ireland suggests that currently 18% of those living with epilepsy have access to a specialist nurse clinic for young people with epilepsy, 47% had no epilepsy specialist clinics at all and 58% had access to specialist nurse clinics for adults. Overall, 78% of parent and carers and 82% of young people were satisfied with the care received from their epilepsy service. Nonetheless, 8% of parents/carers and 7% of young people were not satisfied, particularly due to the lack of mental health advice given. Kobau and DiIorio, (2003), concludes that with self-management of epilepsy and receiving accurate educational interventions individuals can better understand and manage their own epilepsy.

Conclusion

If the correct interventions and supports are not in place, there can be severe consequences which can ultimately decide whether or not individuals will succeed within their education (May and Pfäfflin, 2002). If the person does not complete their education, in some cases, they may encounter future complications when seeking employment.

The aim of this chapter was to review existing and available literature in relation to epilepsy, to investigate the educational supports available to people with epilepsy and to document the potential barriers and challenges faced by young adults on their academic journey. Finally, it provides an insight into the coping strategies used to combat epilepsy and its knock-on effects. The following chapter aims to provide an insight into the subjective experiences of young people with epilepsy and their individual experiences throughout their educational journey.

Chapter Two

Methodology

2. METHODOLOGY

Throughout this chapter the author illustrates the research methodology which was used to obtain and evaluate findings from the data correlated during the process of the study. The chapter focuses on research design, the materials used during research and the recruitment process. It will provide a clear profile of the participants and will incorporate an accurate account of the procedure followed. It highlights and discusses the practical and theoretical rationale for the use of semi-structured interviews as the primary method of gathering data. It will discuss the course of action involved in conducting the actual research. This is followed with a discussion on the ethical considerations and limitations of the research.

2.1 Research Design

Bowling (2002), states that it is essential to make an appropriate choice of research method. As specified earlier in the literature review the intention of this research is to gain an insight into the personal experience of young adults with epilepsy, from their initial diagnosis and the available educational supports. In addition, it attempts to document and analyse potential barriers these young adults face within their educational environment and to examine their relevant coping strategies. Therefore a method which obtained in-depth narrative findings would be beneficial.

A quantitative research which takes shape through the use of questionnaires was considered however questionnaires can often lead to predetermined responses (Britten, 2006). In contrast, the qualitative method takes place in the form of one-to-one interviews and typically produces a more detailed source of data in relation to a defined sample group and cases (Patton, 2002). As Riesman (1993, p.34) states, qualitative data provides “accuracy, richness, contextual depth and diversity”. Taking this into consideration it was decided that the qualitative method would suit this study. This choice of method was reinforced by the fact that it gave participants an opportunity to disclose their experiences and perceptions more so than that of the controlled and reductive procedure of the quantitative method (Bryman 2004).

The researcher was aware that other methods could be utilised in a bid to obtain information, such as focus groups or questionnaires. However, with the quantitative method of questionnaires, as Holliday (2007) points out, one must have good background knowledge on the area in question; know what to ask and how to ask it. Holliday (2007, p.6) observes that the quantitative method "*counts occurrence across a large population*", while the qualitative method *"looks deep into the quality of social life".* Keeping this information in mind the researcher was cautious as the purpose of the research was to provide an in-depth exploration and not merely touch on the surface. The qualitative method was more likely to unveil the necessary information as it facilitates depth and diversity, where quantitative methods may fall short.

A semi-structured interview format with participants, was regarded as most suitable as the objective was to gain an understanding of their personal experiences and their interpretation of these experiences. With regard to the nature of epilepsy and the various experiences of participants' educational settings, the researcher did not wish for anybody to in any way feel uncomfortable while sharing their opinions and experiences. Should discomfort arise, Bryman (2004) notes that individual interviews are likely to be more preferable and that semi-structured interviews enable detailed information on the topic to be disclosed, while allowing freedom of expression and flexibility to both the interviewee and interviewer.

While the interview questions acted as a guide, all questions were semi-structured in a manner that would allow participants to speak as openly and freely as possible on particular topics. From an interview perspective, there are times when opportunities arise to clarify answers and to ask follow-up questions. These opportunities can contribute to the gathering of important information. Rubin & Rubin (2005, p.4) have described qualitative interviews as "conversations in which the researcher gently guides their conversational partner in an extensive discussion. The researcher can extract in-depth details surrounding the research topic by following up on the answers provided by the interviewee during their conversation".

Such interviews can permit the participants to discuss their individual experiences in relation to their journey with epilepsy in the education system, more willingly and honestly. Along with this it is important that the participants are allowed flexibility to outline the issues and events they regarded as important. The qualitative method of research provides a conducive environment where this can take place.

2.2 Recruitment of Participants

Purposive sampling was used for this study. Purposive sampling, often referred to as judgement, subjective or selective sampling is a non-probability sampling method. This method is characterised by a premeditated effort to increase representative samples by including particular areas or groups in a sample. When selecting sample group members, the researcher depends on his/her own judgement. Purposive sampling is most common in qualitative research. The researcher has an adequate amount of knowledge on the topic which allows them to select the sample. Subjects and experts are chosen by this method depending on the type of topic. Therefore the capabilities and skills of the researcher to find and include the correct individuals will contribute to the success of the research when using this technique. The researcher, in this case has experiences of living with epilepsy on a day-to-day basis for over seventeen years, therefore having knowledge of the topic and previous experience within the chosen programme, allows them to select a particular sample group which will contribute to the success of the study. However, the researcher is aware that their own personal experience could possibly influence elements of judgement, subjective or selective possible bias and acknowledges this when collecting data and throughout their entire research process. The results of the purposive sampling method are more often than not representative of the targeted population in comparison to other sample methods. Purposive sampling can often be the only way to recruit members of much sought after or rare groups. It is also associated with limited representation of extensive populations and exceptionally high levels of subjectivity by the individual researcher (Palys, 2008).

The researcher made contact with the course manager, who is located in Sligo I.T, to explain the purpose of and seek permission for the study. This was approved (Appendix. 2).

The researcher requested the assistance of the course manager, to act as a ‘gate-keeper’. The role of a gate-keeper in the research process according to Barbour (2008) is to help protect the interests and rights of the participants involved in the research. Daymon & Holloway (2011) acknowledge that from an ethical point of view it may be difficult to enlist participants and to gain access to their personal information which is the starting point in the research procedure.

Provisional discussions took place, prior to December 2015. The researcher travelled to Sligo I.T to meet the potential participants and to explain the purpose of the study. Prior to the commencement of interviews, approximately five to seven participants had volunteered and been recruited by the course manager to take part in the study. However, on the day of the interviews, ten participants were interviewed. The reason being, participants and other students from the programme heard about the study been carried out and wanted to also share their experiences of their initial diagnoses and have their experiences and views voiced on their academic journey. The gate – keeper assisted the researcher in ensuring that the extra three participants, who wanted to take-part on the day, received adequate information on the process of the semi-structured, one-to-one interviews and reasons for the study being carried out.

2.3 A profile of participants

To protect confidentiality, the names used in the table are not the real names of the participants and the pseudo names are for illustration purposes only.

Table 1 – Profile of Participants'

Name	Gender	Age	Diagnosed at	Level of Education to date
Mary	Female	22	15 years	Secondary level (5th year)
Michael	Male	24	2 years	Third level (2nd year)
Ethan	Male	18	0 – 3months	Secondary level (Leaving Cert)
John	Male	22	18 years	Third level (completed)
Paul,	Male	19	4 – 5 years	Secondary level (completed)
Ann	Female	19	17 years	National level (6th class and home schooling)
Kurt	Male	25	1 years	Secondary level (5th year)
Tom	Male	47	40 years	Secondary level (completed)
Ursula	Female	18	15 years	Secondary level (6th year, didn't complete)
Brian	Male	25	16 years	Secondary level (3rd year)

It is important to make note of, quotations from participants are Verbatim, meaning when you quote someone exactly without changing anything

Profile of participants' status presented as follows:

Nine participants held single status and one participant was of married status with two children. On the day of the study being carried out, the occupations of all 10 participants were students, completing a transition course. The programme, is not a third level course, even though it is based on the grounds of a third level institute. It is a transition course for students from secondary level to third level education which offers useful skills and insights into the next steps the education level.

The final sampling response rate due to the extra participants on the day was increased to 10 interviews taking place.

2.4 Research Materials

Barbour (2008) is of the belief that the use of a recording device is of great value to research as it can store a large amount of vital information. As a result the researcher was aided by the use of a Dictaphone. Prior to any recordings taking place, all participants signed a consent form (Appendix.5) stating they were eighteen years of age or over. The consent form outlined the purpose for the use of a Dictaphone.

Prior to the interviews commencing an information sheet was delivered to the participants so that potential participants were informed appropriately, (Appendix.4). A list of interview questions was received by all participants to help them prepare for the interview on the day (Appendix.6).

2.5 Procedure

Stage – 1 In September 2015, prior to the commencement of the research, the researcher wrote via email to the course manager at Sligo Institute of Technology. The programme has had over 250 young people with epilepsy attend since its inception in 1998. It is the only course of its kind anywhere in Europe and has had students from over 26 counties attend. The course is for one year and provides practical skills, developing self-confidence, progression & a Level Four Fetac Qualification. It is a transition course for young adults living with epilepsy, teaching them how to live actively and positively with epilepsy. The course also enables students to progress into third level education.

On 29/01/2016, the researcher wrote a letter to the course manager. The purpose of the letter was to inform her of the author's course of study and research requirements and requested permission to gain access to students to conduct the relevant research. It outlined the proposed research topic, target group, procedure and the specific reasons for conducting the study with students on the course (Appendix.2). The researcher's name and contact details, as well as assurance of confidentiality in relation to any information obtained during the research were included.

A second letter dated 12/02/2016, explaining the aforementioned study was forwarded to the Head of School at Sligo I.T., Dr Perry Share. This letter requested permission to complete the study on the grounds of Sligo I.T., (Appendix.1). Previously in December 2015, when the researcher met with participants prior to carrying out the study, the researcher explained that the interviews would take place at later date in April 2016. The majority of the participants on the course agreed to take part but with some participants' availability dependent on the selected date, scheduled doctor's appointments and/or planned work-placement.
Those who agreed to take part in the study were informed on December 2015 in advance that they were under no obligation to partake. They were informed that they could decline to answer any question if they felt uncomfortable and could terminate the session at any time. Each participant was informed that they could choose to have a copy of the transcript once completed.

Stage – 2: Tuesday 12th/April/2016 the researcher received ethical approval from the School of Science/Department of Humanities, Ethics Programme Board in Athlone Institute of Technology, following recommendations. Following this, arrangements were made for semi-structured one-to-one interviews with participants. Prior arrangements had been made for approximately 5 to 7 participants to take part who were recruited by the course manager.

Stage – 3: Arrangements were made through e-mail with the course manager (gate-keeper) to further explain the research to the participants and also to help participants prepare for interviews. A list of questions was provided a week prior to the interview being facilitated. The gate – keeper and another member of staff spoke with the class and reminded the participants about the research, providing a brief discussion and description on the purpose of the research due to be conducted. Once the research was discussed and questions were answered, the gate – keeper delivered information sheets and consent forms to all participants and clarified the contents of them to each individual. During the discussion, it was explained to participants once again about a recording device. The lecture clarified the reasons for the use of a recording device and participants agreed that this was not an issue.

Stage – 4: Monday the 18th of April 2016, the researcher travelled to Sligo I.T., and was re-introduced to the participants' of the research. The author outlined the purpose of the interviews; which was to establish their personal experience and views. The researcher stressed that there are no wrong or no right answers. It was important just to feel comfortable, at ease and be able to express how they really felt or thought in a particular situation. An open-hearted welcome was received by the researcher from all staff members and participants. Previously, it had been arranged that a room adjoining the participants classroom was be used for the interviews, however, a separate classroom next door to the participant's classroom became available on the day and this was then used for the interviews. Before any of the interviews commenced that morning while participants were having a conversation amongst themselves, some had said that they were slightly nervous because, although they knew their classmates would not hear anything of what was being discussed during the interview, they could still visibly see them in the adjoining room. When a separate classroom with no direct visibility became available, it was more beneficial to the studies, as participants appeared more willing and comfortable to share information of their own personal experiences.

In advance of the interviews beginning, the researcher tested the recording equipment, checking the sound was at an adequate level for the room.
It was clarified to all participants' that confidentially would be upheld and only pseudo names would appear in the context of the research. Participation being voluntary was outlined in the information sheets (Appendix .4) and was restated once again by the researcher reminding participants that they could withdraw from the study at any given time.

Reading out loud the contents of the consent forms, the information sheet and the list of questions aided participants and helped clarify what was required of them, as participants stated this was helpful. The researcher obtained the consent forms from all of the ten individuals (three females and seven males) for the semi-structured, one-to-one interviews. (Appendix. 4, 5, 6). According to Amaro (1995), the complete contribution and consent of those affected by a specific issue in developing change are vital, while understanding their concerns.

Stage – 5: Semi-structured interviews were conducted with participants who experience life with epilepsy on a day-to-day basis and are attending the programme. All participants in separate interviews were asked the same list of questions, which lead to the researcher gathering unique information from the individual participants, some where they encountered different experiences and some having common experiences within the education environment.
Participants involved all had similar views and different experiences. The researcher, alongside the course manager acknowledged the importance of participants having their voices and opinions heard and it was a valuable contribution to the research outcome. Interviews had expected to last 40 minutes but ranged from 20-40 minutes, depending on the participants' individual experiences.

Stage – 6: Following the interviews, the participants were asked if they would like to receive a copy of the finished dissertation. Both the participants and course manger acknowledged this with great anticipation.

2.6 Ethical Considerations

According to Hand and Hillyard (2001; p.59) the application and development of research ethics is necessary *"not only to maintain public confidence and to try to protect individuals and groups from the illegitimate use of research findings, but also to ensure its status as a legitimate and worthwhile undertaking"*. The researcher put a number of measures in place in order to ensure ethical practice. Prior to the interviews taking place, the author prepared a letter of consent for the semi-structured interviews (Appendix. 5). These letters explained specifically what the interviews would involve and requested to record the interviews for the purpose of transcription. Transcription can often be a long and tedious process, but as Hand

and Hillyard (2001) suggests, tape-recording is important at this stage as it enables the interviewer to hone in on the actual conversation as it took place, this in turn supports interpretation.

The right to confidentiality and anonymity was also guaranteed. According to Sarantakos (1998) any information given by the participant should only be used by the researcher and strictly for the purposes of the research only. Each participant gave verbal and written consent for the semi-structured interviews to be recorded. The participants were also guaranteed confidentiality and anonymity along with the reassurance that no identifying information would be used in the final report. In addition, all participants were informed that all transcripts of the interviews would be kept in locked storage and that all computer files would be password protected. Given the sensitive nature of the research, a guarantee was given that the researcher would transcribe the interviews alone but their supervisor would be the only other person who would be granted access to any information there within.

The researcher put special arrangements in place to deal with the issues of vulnerable participants, such as modifying their consent forms. This was to prevent a situation arising if participants presented with an intellectual disability, as the researcher was aware they did not present with any physical disabilities. The researcher drafted a consent form enabling a third party to be present during the interview process. Also to ensure all participants were 18 years and over and to obtain relevant informed consent an additional section was added to the consent form.

To prevent possible discomfort or distress either physical or mental, due to the sensitivity of the subject, the researcher compiled a leaflet for all of the participants so that if any sensitive issues arose, contact details of various support groups and college counsellors would be available to access if required. This leaflet also included details of the local and regional epilepsy nurse. A guarantee had been given that the epilepsy nurse was aware of the study and was on standby should anyone get distressed during the interviews.

2.7 Thematic Analysis

Following on from the interviews, a typed transcript was completed of each interview. On several occasions the transcripts were read and re-read in order to find developing themes. Once themes developed and became obvious, the researcher started coding the data and developing a thematic analysis. Coding refers to a tool for thoughtful ways of processing the meaning of data and for decreasing the large volume of data (Huberman & Miles, 1994, cited in Denzin & Lincoln, 2000). Using different coloured highlighters to highlight the developing themes, coding was carried out. This identified many different developing themes from the discussions. In addition, sub- themes arose which delivered further in-depth information to the analysis.

Bryman, (2008), states that the discovery of the developing themes needs to be outstanding and similar to that of other findings. The researcher used blind coding for the analysis of the transcripts in order to obtain and to identify what themes arose in the transcripts.

2.8 Delimitations of the Study

Each research has its own limitation, according to Bryman (2004) quantitative researchers occasionally analyse qualitative research as being too *“impressionistic and subjective”.* The main instrument for gathering information is the interviewer. The interviewer determines which areas are given more attention. Wilkinson (1998) cited in Shargel, (2000), points out the importance for the researcher, to have an ability which allows them clearly explain the angle from which they approached the material. This will help them to overcome any issues that should arise. The following are the delimitations:

1. The need to travel a distance to gain access to the participants. This was a time constraint and out of the researchers control. It put added expense on the researcher for fuel and as the researcher does not personally drive, they had to ask others to drive them on the two occasions.

2. The researcher’s bias to the subject matter that was been researched, as the type of sampling used “purposive sampling” allows for judgement to be passed on participants. This sampling goes on your own knowledge and experience of the subject been researched. As the researcher, a surety that boundaries were in place and that personal experience of epilepsy did not interfere with participants’ responses. The researcher could be quick or difficult to defend a position when

publishing their findings. This is why researchers need to ensure that they use a recognised standard which is based on correct procedures rather than what will best support the theory. A researcher needs to defend effectively their suggestion from their participants. It can be more problematic for a researcher to find a concrete defence due to the nature of non-probability of purposive sampling. One may dispute that if other choices were made throughout the purposive sampling, a diverse result could have been accomplished. However, further research could take place to compare the findings (Palys, 2008).

Conclusion

This chapter outlined the research design, materials required, recruitment of participants and provides a clear profile of the participants and incorporates an accurate account of the procedure that took place. Delimitations and ethical considerations were also examined.

This research is carried out within a framework of qualitative method with a semi-structured one-to-one interview taking place with individuals who have personal experiences of living with epilepsy on a day-to-day basis. In carrying out this research, the author drew on critical literature and writings about epilepsy as a hidden disability for young adults within the education environment. The next chapter will discuss the findings of the research and the thematic analysis presented.

Chapter Three

Results

3. Results

The author will produce the findings of the qualitative research in this section, which were explored and examined by means of thematic analysis. This was to create awareness about epilepsy and to investigate the possible challenges faced by young adults with epilepsy, during their academic journey.

The personal experiences and views of the participants have proven to be very valuable to the study. This chapter sheds light on recurring themes, reproducing what was measured to be important by participants who took part. The findings are divided into section one and two and based on the aims and objectives, where the recurring themes which developed will be deliberated.

3.1 Section One findings

Objective One: To gain an insight into their personal experience of initial diagnosis and the educational supports available.

Table 2 – Different types of Seizures

Partial Seizures
Simple Partial – Can involve sensory, motor, psychic or autonomic symptoms.
Complex Partial – Person may appear dazed and confused.
Generalized Seizures
Tonic Clonic seizures 'Grand mal' – Tonic phase typically involves a crying or groan, loss of awareness and a fall as consciousness is lost and muscles stiffen. Clonic phase, typically involves convulsion, jerking and twitching of all four limbs.
Myoclonic – Sudden jerks such as the arms or legs. The person may fall down.
Absence 'Petit mal' – Results in blank stare.
Photosensitivity - light stimulation

The types of epilepsy reported by participants are summarised in Table 2 with absence, tonic clonic and complex partial seizures being the most frequently reported types of epilepsy. Some participants would have only one type of seizure whereas another participant could have two or three types of seizure, depending on what part of the brain was affected with the epilepsy, as the seizure could start in one part and may progress onto another part of the brain. Participants reported that the occurrences of seizures varied with some having three to five seizures per week, others encountering one or two per month and others not experiencing any seizures at present due to medication controlling there seizures.

Table 3 – Section One – Objective One – Headings and Themes

Heading	**Theme**
3.1 (a) **Personal experience of initial diagnosis**	*1) Surprise and upsetting emotions* *2) Career Change* *3) Memory* *4) Eye sight and concentration levels*
3.1 (b) **Educational supports available.**	*1) Understanding and knowledge of Epilepsy in schools* *2) Academic support available in national and secondary level* *3) Academic Supports Available in Third level*

3.1 (a) Personal experience of initial diagnosis

Living in fear of when seizures will happen can be extremely devastating and make you feel apprehensive. Participants were asked about their experience with epilepsy and their initial diagnoses, what age did they developed epilepsy and how they felt when they realised they were diagnosed. Participants had unique experiences as to what stage in life they developed epilepsy and how they felt once they first realised they had epilepsy. Participants' initial diagnoses ranged from as young as one years old to developing epilepsy at forty-two years of age.

i. ***Theme One:*** *Surprise and upsetting emotions*

Surprise and upsetting emotions were some of the initial themes that became noticeable. Participants, reported experiences of feeling "different", "odd", "weird" and "distant" to many of their friends after receiving their initial diagnoses.

This can be seen in pieces such as:

Mary, 22

"*That was a big shock for me but my friends are now thinking I am odd"*

And similarly:

Brian, 25

"*I have lost my friends now since I have epilepsy, they would have been around me before I was diagnosed, and now think I am a freak or something*".

Epilepsy can be terrifying and the anxiety about seizures is reasonable due to its unpredictability. However educating oneself and others about what occurs during seizures or talking about fear, may aid to decrease this anxiety.

ii. ***Theme Two:*** *Career Change*

Living with epilepsy can create many limitations when it comes to work and career choice. The initial diagnosis of epilepsy can disturb people in different ways. The theme of 'Career change' was discussed frequently during the interviews. Participant remembered their own personal experiences of when they were initially diagnosed and what this meant to their career.

Michael, 28

"*Life shattering, the reality is, I was to be a Sous-Chef in Australia and it didn't work out".*

Ethan, 18

"All my life is ruined, I cannot do work that I like. I wanted to be a police-man but later found out I can't because of epilepsy".

Tom, 47

"*Basically I had to change my whole career, not been able to drive for work and getting on ladders wouldn't work well with epilepsy".*

Brian, 25

"I think the realisation of what came with epilepsy, the challenge of every career path I take, is it safe for me and others? No matter what you do, it is never just me involved, it concerns everyone, school, career, social life, challenging to me and others, because no one wants to put others out, it's fear that each seizure you have, you know already puts fear in a person, family/friends, so each day, it is a constant challenge".

As individuals, being capable to live life safe and well is important. Finding a balance between the conditions, independence and keeping safe are vital. The initial anxiety is understandable, however, learning about epilepsy and your potential capabilities related to the condition can keep people with epilepsy safe and independent. Finding out information about the condition and asking questions can be useful to people. Epilepsy Ireland provides emotional support and information for anyone wanting to know more about epilepsy. Communicating through the epilepsy nurse or confidential phone-lines may help individuals gain knowledge and understanding on how to manage living with epilepsy.

iii. ***Theme Three:*** *Memory*

Participants were asked if the medication prescribed for their epilepsy affected them in any way with their education. Memory difficulties can have enormous impact on individuals living with epilepsy, that it may affect their performance at school, work, and home.

Mary, 22

“*The medication prescribed has affected my memory, especially when I was first diagnosed, my whole short-term memory was gone. I forgot my own birthday, my middle name”*.

Including how medication prescribed effects education attainment:

Mary, 22

“*Exams suffered, because of my memory, when I compare it to 1st – 3rd year, when I didn’t have epilepsy, I completely flourished like, I was a straight honours student, but now I am not sure if it’s the epilepsy or the medication or a mixture of both, I started having to drop to ordinary level in every subject*”.

Seizures in the left temporal lobe, right temporal lobe and in the frontal lobe effect memory and an individual might find it hard to remember things from the past or that they have to do in the future. Seizures can affect your ability to take in, retrieve and store information. This can happen after or during a seizure. It may be an enduring matter (e.g., triggered by your medication) or it may happen just after a seizure. Having different memory aids may support the young person to cope with memory difficulties such as diaries and ‘to do’ lists, sticky notes as reminders and having a drug wallets (pill boxes) etc.

iv. **Theme Four:** Eye sight and concentration levels

Concentration levels and eye-sight can be effected both during a seizure and afterwards if the brain is feeling stressed or anxious it will more likely have difficulties at the ‘learning’ stage. Participants were affected with concentration and eye-sight due to medications prescribed, all of which had an effect on their education.

Ursula, 18

“Would be tired, find my eyes are gone bad, I wouldn’t be able to concentrate or the same when I was on Keppra medication, I was lashing out at people, I didn’t know where I was or what I was doing”.

Similarly:

Brian, 25

“Concentration is bad, I can only focus on one thing, I need structure. My eye sight is terrible and my memory is concerning me, I would have done something ten minutes ago and not remember, this affects me in trying to get good education scores”.

Strong side effects of prescribed medication, while it may be of benefit for a person’s epilepsy, it maybe questionable, if it is detrimental to their intellectual abilities. Therefore, regular monitoring of prescribed medications and where necessary, changing doses and medications, needs to be considered in line with education attendance.

3.1 (b) Educational supports available

Training is required for administration of emergency medication, i.e. buccal midazolam, which is given into the buccal cavity, side of the mouth between the cheek and gum. There should be a care plan in place for the administration of emergency medication at school. All participants were asked, what supports were given to them with regards to the management of their seizures and administration of medication during school hours.

i. ***Theme One:*** *Understanding and knowledge of Epilepsy in schools*

Paul, 19

“The principal would give me medication if I had a seizure and my parents had to be called because the teachers were not very aware of my medication or my epilepsy, they didn’t really understand”.

Ursula, 18

“*The school was great. The principal got anything I needed, like she had a couch in her office, the nurse would stay with me and took records needed for the doctors”*.

Allowing for 12 hour intervals, AEDs are usually taken once or twice a day, which regularly happens outside school hours. However, if an individual needs AEDs during school, having a health care-plan means their medication is managed. This plan can be organised by the school and approved with the principal and family.

While the above showed that understanding and supports where available in some educational environments, this was not the overall experience. In some cases, the education system was unhelpful and did not understand epilepsy as family members were called to assist as can be seen from the following quotations.

Brian, 25

> *"In school there was no supports, the teachers just didn't have a clue, I did think it was normal after having a seizure, I thought it was what teachers had to do, I was put outside my classroom, left on a chair, sitting waiting for my parents to collect me because the teacher was afraid, that's why I left in the end".*

Ann, 19

> *"Not in my school no, nobody was educated on epilepsy, this was actually my mum who educated the school on it and people still didn't understand, even though we tried to tell them"*.

Kurt, 25

> *"I got detention in secondary school more than once but now I know I was having a seizure".*

Teachers are vital role models for young people with epilepsy and have a lasting impact on the educational performance of young people, predominantly individuals with epilepsy. Negative attitudes, misconception or discrimination, mainly in social environments like schools, can initially disturb the quality of life of young person. Some students do not achieve well in school and some present with learning difficulties in social interactions. However, lack of knowledge and awareness about epilepsy within educational environments can be damaging, therefore, an urgent need for awareness and knowledge within the educational services needs development, and a possible educational campaign directed especially towards teachers informing them about epilepsy is necessary.

ii. ***Theme Two:*** *Academic support available in national and secondary level*

Epilepsy is a condition that is covered by the Equality Act (2000), even if a person's seizures are controlled with medication. Therefore it is against the law for training providers and education to discriminate against people with epilepsy. It includes all educational environments. Participants expressed doubts about academic supports being available and were apprehensive during national and secondary level education about the lack of academic supports available to individuals with epilepsy within their education environment.

Ann, 19

> *"Nah, I didn't see any"*, concerning academic supports available

Also similarly,

Brian, 25

> *"Not for people with epilepsy, I ended up leaving school because the school did not know how to cope with epilepsy, no matter what they were told from by my parents they just didn't understand, so I had to leave and did not get the chance to complete my Leaving Cert"*

The responses demonstrates that these education environments do not have enough awareness and knowledge about epilepsy, and how it effects an individual's learning ability. A suggestion for rectifying this and reversing the lowered levels of education attainment, could be for the education boards to co-ordinate in consultation with the medical professionals and compile a training programme to inform school principals and teachers about the nature of epilepsy and education.

Some positive academic supports were available, however, individuals were not informed, were late into education when receiving these supports or did not receive the correct supports.

Michael, 28

> *"There was but I didn't get it, um, I was not aware, probably was accessible, I just didn't know what I should have been looking for".*

Even though the obligation is on the education system to provide supports, in many cases the supports provided were poor or came too late to make any difference.

Mary, 22

> "*There was but not until I was in 6th class, I was taken out of another class and this support was not for the epilepsy*".

Equal experiences happened to,

Ethan, 18 and Paul 19

“Yes later in school, I got an SNA and for Junior Cert exams I was put away to a different room that I didn’t like”.

The remaining participants explained their experience of primary and national education where they did not come across any problems.

In light of the above comments, urgent academic supports are of necessity. Informing and communicating with schools must be a necessity of the individual and the family, in order to achieve better education performance. The need for remedial supports, resource assistance and educational interventions must be made a priority in the educational environments.

iii. ***Theme Three:*** *Academic Supports Available in Third level*

Third level education disability services are made available and provide assistance in finding what academic supports are available. While third level educational environments have an obligation to support and provide assistance to individuals with disabilities, only if a student informs them of a disability, can the service provide assistance.

Kurt, 25

“Supports are made more known to you, like there is supports for people with epilepsy now, like extra time in the exam”.

John, 22

“*It is a bigger mix, more options, you’re actually told things”*.

Epilepsy is an “unpredictable” condition and can develop at any stage in life. Some participants developed epilepsy after they had passed through secondary education, so only experienced it while in third level.

3.2 Section Two findings

Objective Two: To document and analyse the potential barriers faced by these young adults within their educational environment; and to examine their relevant coping strategies.

Table 4 – Section Two – Objective Two – Headings and Themes

Heading	**Theme**
3.2. (a) **Potential barriers**	1) *Friendships* 2) *Side effects to medication* 3) *Social Isolation and restriction*
3.2. (b) **Main challenges**	1) *Fear of a seizure* 2) *Social Life* 3) *Stigma*
3.2 (c) **Coping strategies**	1) *Medication* 2) *Knowledge of triggers* 3) *Realisation*
3.2 (d) **Important supports that should be available.**	1) *Suggested Supports* 2) *Lack of Mental Health supports available*

3.2 (a) Potential barriers

Participants who developed epilepsy in later life and not at a young age such as childhood, i.e. adolescents or adulthood, all noted a change within friendships from close friends, outside and within school.

i. ***Theme One:*** *Friendships*

During school journey Jacoby (1996) states an individual has accepted their epilepsy, they are able live a normal life, only making slight changes where necessary. If individuals drive or have a way of getting around, it is easier to keep in touch and show an interest but when this is taken away it is easy to lose connections with close friendships. When still in school, the lack of knowledge and understanding of the condition can lead to problems with friendships and isolation due to fellow learners' misunderstanding and fear (Marcon, 1999).

Ethan, 18

"*I had problems with students, they thought it's the way I behave and they'd make a mess about me*".

Kurt, 25

"I had to drop out because it wasn't any good with my epilepsy, so I got transferred to another school that helped me more".

Resulting in,

Kurt, 25

"Took away all my friends when I move schools and I wasn't able to do the same tests as them".

Others were unhappy with the education system as they voiced a strong view on the lack of education for teachers and saw it as a specific barrier when attending school in regards to epilepsy.

Brian, 25

"Yes, the teachers not knowing what to do if I had a seizure, being afraid, made me lose friends in the class and made them afraid of me, my friends wouldn't come near me afterwards".

There was a common harmony between many participants about barriers to friendships, as many said, "*I have lost many friends"* or *"people I thought were my real friends*" "*find it hard to get a girlfriend, like a long-term relationship, they're afraid of you, look at you like a freak",* Each participants said their epilepsy was a major barrier to either keeping friendships they previously had or find great difficulty in creating new lasting relationships, because of their epilepsy.

ii. ***Theme Two:*** *Side effects to medication*

There was a common harmony between participants as they experienced side effects of medications prescribed for their epilepsy and see them as a potential barriers.

Ethan, 18

"Side effects of medications is a barrier to my education, it causes problems with me concentration and I'm constantly tired in classes".

Ursula, 18

"*Oh yeah, I had to stop doing everything I enjoy, my art in school because of the side effects to my medication, it kept making my hands shake".*

iii. ***Theme Three:*** *Social Isolation and restriction*

Social isolation and restriction is the complete absence of interaction between an individual and society and a limit placed on an individual. It differs from loneliness, which echoes participants' responses:

John, 22

"*More myself, in my own way, I got scared, then nervous to have people see me in a seizure"*.

Compare to limits placed on,

Ursula, 18

"*Allowed do nothing anymore, my family won't let me anymore, I hate it".*

All participants commonly faced potential barriers with *"not been able to drive"*, *"having a normal social life at my age"*,

Ann, 19

"Relationships, having a boyfriend, your always worried what if it happens and getting them to understand".

Tom, 47

“Getting people to trust you to look after children on their own”.

3.2 (b) Main challenges

Young people do not want any confusing factors, but epilepsy is just that. In a time of life marked by many changes on the hormonal, mental, physical and social level, epilepsy can create an added complication at a sensitive time in the development of a young person.

i. ***Theme One:*** *Fear of a seizure*

Fear of a seizure occurring at any time was a constant theme throughout the study. Fear is an unpleasant emotion caused by the threat of danger

Mary, 22

“Being terrified I’m going to have a seizure all the time, not knowing where I am going to wake up”.

ii. ***Theme Two:*** *Social Life*

An essential impact to human being mental health is the individual social life, which reflected as a recurring theme in the study.

Paul, 19

“Going around with my friends in town, I’m worried about having seizures in front of a load of people”.

iii. ***Theme Three:*** *Stigma*

Gordon & Sillanpaa (1997) argue that other in society will agree, if the individuals themselves accept that their condition carries a stigma.

Michael, 28

“Unfortunately absolutely everything, it’s the interpretation of everyone around me that seems to come with it, like it’s a big weight and I don’t know how to deal with it”.

All participants described *“trying to keep positive, with negativity”* is a challenge. It is apparent that epilepsy is still surrounded by stigma, from responses received.

Epilepsy Ireland, is an educational service for epilepsy which can reinforce knowledge and awareness within society.

3.2 (c) Coping strategies

Epilepsy can make life stressful, worrying or cause anxious and depression. These emotions can disturb an individual's general well-being. Taking control and finding coping strategies can help reduce the impact of seizures on a young person's emotional and physical well-being.

i. ***Theme One:*** *Meditation*

Meditation is effortless and leads to a state of thoughtless awareness. (Hassed, 1996). The following quotes are in response to the researcher's question about coping strategies used:

Ann, 19

"I use meditation, kinda to relax myself"

Ursula, 18

"A lot of meditation, the lumber puncture just your finger, sometimes if I feel a seizure coming on I'll use the breathing 7/11/4 deep breathing exercises".

Kurt, 25

"*Deep breaths and just try my best"*.

Participants were in agreement that using meditation as a coping strategy for their epilepsy was beneficial to them.

i. ***Theme Two:*** *Knowledge of triggers*

Triggers are circumstances that bring on seizures and differ from person to person. Individuals living and learning about their condition daily and knowing what triggers a seizure may lessen the chances of having a seizure.

Tom, 47

"I know stress and not enough sleep triggers seizures, I try not let myself get tired and relax if I'm stressed out".

Brian, 25

"I try not to let things get on top of me, I don't let it build up on me. I'd make sure of my sleep, take my medication, but I'd have regular meals. Um, stay away from alcohol because I know that triggers my seizure".

iii. ***Theme Three:*** *Realisation*

Realisation and understanding of the condition was of importance to the participants'. If young people come to terms with their own condition themselves then a sense of confidence and not defence can affect the individual's experience of life (Rogers, 1961).

Brian, 25

"The realisation of everything that comes with epilepsy and how it affects absolutely everyone and everything involved with me. My family, my friends, where or what I can work, my education, um practically every single thing I do in my daily life I have to consider it around my epilepsy, and I think for me, a big coping strategy was learning to realise all of this over time and dealing with it daily, because the reality is, I don't have a choice anymore now that it is here".

Ethan, 18

"I think by the time I came to terms with my epilepsy, all my school friends had moved on, so realisation was my coping strategy and what I needed to do for me. Um, not many understood it so I had to come up with things that helped me, like me being selfish and looking after myself firstly and then others"

3.2 (d) Important supports that should be available.

Providing the researcher with such a diverse group of experiences, participants spoke of the need for personal support groups where young people can meet and share experiences. A support group available seems to be influential to individuals in providing knowledge on the condition but also help educate society to reduce the negative stigma felt by young people.

i. **Theme One:** *Suggested Supports*

There was a strong consensus between participants as to how important it is that supports should be available to both people with epilepsy and people who do not have epilepsy, as it is not spoken about enough.

Paul, 19

"You are not wanted around because the fear you might have a seizure, it's this 'freaky thing' and no one will know what to do"

John, 22

"*Definitely more counselling needed for people with epilepsy*".

Every participant involved in the research suggested that more awareness and education is needed about epilepsy everywhere, i.e. Education environment, friends, family, and society in general because there is not much out there.

ii. **Theme Two:** *Lack of Mental Health supports available*

Numerous participants spoke about the lack of mental health support available for people with epilepsy and that there should be more made available.

Michael, 28

"Became incredibly depressed, it pushed me to a suicide attempt".

Mary, 22

"For 2 years I wouldn't leave my house, I developed OCD[1], I'd avoid everything just before a seizure because I thought if I did that, I would have a seizure".

Unfortunately, situation like these do occur due to the lack of adequate support services for the mentally challenged, including PWE[2].

Every participant agreed and suggested that a *"support group"* should be set up for people with epilepsy. Mary, suggested "*an "AA meeting", where everyone meets up in a group where they can sit and share their problems and things like that".*

---

[1] Obsessive Compulsive Disorder (OCD)

[2] People with epilepsy (PWE)

Conclusion

All participants see it as their responsibility to inform others of their condition, including the principal, teachers, parents and friends, to avoid them getting a shock when a seizure was to occur.

Overall, the two main barriers that affected participants was a lack of knowledge and the attitudes of academics in secondary and national level education including the access to education services within the different levels, highlighted by the young adults who had experience in different stages of education.

This concludes the findings of this present research. The following section explains in detail the themes which arose in relation to current and factual literature.

Chapter Four

Discussion

4. DISCUSSION

In this section, the discussion will evaluate the findings and how they are interpreted in terms of how they contribute to the current body of knowledge on the topic. The qualitative research undertaken by the author provided motivating findings, which will be deliberated in detail below. This study aims to create an awareness about epilepsy and to investigate the possible challenges faced by young adults with epilepsy during their academic journey. The structure of the discussion will be in accordance to the objectives of the research.

4.1 Summary of findings:

This research has given valuable insight into the experience of individuals living with epilepsy in the context of the statutory education system. Participants have outlined how they were subject to exclusion because of their epilepsy and the lack of awareness and knowledge in the educational environments was consistently reported. Overall, key findings separate to the educational environment, showed that young people with epilepsy faced barriers and challenges daily, due to medication, career changes, family members been over protective thus not achieving their own independence and not having appropriate support groups available when essential to their needs.

Objective One: To gain an insight into their personal experience of initial diagnosis and the educational supports available.

4.2 Personal experience of initial diagnosis

Epilepsy is an enduring neurological disease affecting people of every gender, age, race and socio-economic background. The optimal management and diagnosis relies on the influence of a number of healthcare settings and a selection of healthcare disciplines. The findings of the present study suggest that the initial diagnosis caused participants and their families' to experience feelings of fear, shock and confusion but also misunderstanding, both in terms of the lack of information that was received about the condition and the general languages used when diagnosed with epilepsy. A participant stated, “*They never used the word, epilepsy. It was ‘attacks’, ‘fits’ and this is why there were delays making correct diagnosis. We did not understand, nor were we never told*”.

This directly contrasts with, Sillanpaa (1992) who recommended that a clear diagnosis be communicated to the individual and their families by all relevant medical professionals, both from initial diagnosis and across all follow up care. Receiving an initial diagnosis of epilepsy can impact on an individual’s life and career choices enormously. Examples of this are regular daily medication with the aim of controlling seizures, the impact on family members to provide care and the personal barriers such as being unable to drive.

4.3 Medication prescribed for epilepsy affect education

“I must take my medication on time. If I don’t take it, blood levels drop and I can’t prevent a seizure happening, it is not nice, watching the clock”.

Findings from the present study showed that most frequently reported types of seizures were absence, tonic clonic and complex partial seizures with Keppra, Epilim and Clobazam being the most commonly prescribed medications. These findings correspond with Reynolds and Trimble (1981) cited in O’Donohoue (1994), who stated, there are concerns over AED’s impairing individual performance at school, as they may have negative effects on both behaviour and cognitive function. It is imperative to recognise that simple partial and complex partial seizures may develop into secondary generalised seizure (See Glossary)

Findings showed that some participants did not have significant knowledge about their own epilepsy, and therefore had difficulties informing others about their condition appropriately. Participant stated,

“I think I fall down and have all the types of seizures”.

Gordon and Sillanpaa, (1997) suggests that the individual’s extensive knowledge contributes to the better handling of the condition and is significant in developing effective coping strategies. The results of this study suggest that knowledge of the condition can be challenging for some living with epilepsy, and this may have a direct negative effect on the way individuals manage and cope with the condition.

Similarly, Ward and Bower (1987) state that the aim of handling the condition or treating it to reduce or eliminate seizures and to help individuals lead a productive and qualitative life, minus major side effects of the treatment involved. This is not always achievable as participants reported various side effects involving memory loss, concentration problems and poor eye-sight after being prescribed epilepsy medication. Other areas such as behavioural issues, tiredness, headaches, drowsiness and mood swings in addition to the above, create constant barriers for the individuals. Participants stated, due to side effects of medication that,

> "*My mood would be go from great form to like a bomb hit the room in seconds"*

This in turn affects education, which makes the suitability of the medication prescribed questionable for the individual. While the role of prescribed medication is to reduce or eliminate seizures, it should not to prevent individuals from living a full and productive life whilst achieving a standard education attainment.

4.4 Are educational supports available?

Epilepsy is a hidden disability and for this reason it is not recognised under the Education Act (1998) under the term 'disability'. It is more so defined as "a malfunction or condition, which effects a young person having to learn differently from the person without the malfunction or condition", or "illness or condition which affects a young person's perception of reality, thought processes, judgement or emotions or which results in disturbed behaviour" (S21). To be able to understand epilepsy and how it effects individual's school performance, all academics need to have the necessary knowledge and awareness of various hidden disabilities.

Besag (1994) states that most individuals with epilepsy have poor academic attainment within the educational environments, and most academics are lacking the appropriate training, knowledge and awareness to help provide adequate educational provision. Present research findings, suggested that if participants had been aware of the supports and interventions available, their education attainment would have been significantly higher, with one participant who was not diagnosed until after educational years, however, three participants completed secondary level education and one completed third level education, but the remaining six participants did not get to complete education either due to their epilepsy causing issues in the educational environment or the lack of educational supports available. Besag's theory (1994), concurs with present findings, that a considerable amount of individuals suffered because of the inaccurate level of educational attainment, due to the lack of knowledge about epilepsy within educational environments and supports not being developed and provided. May and Pfäfflin, (2002) have suggested that it must be ensured that significant interventions and supports are identified and introduced for students with a disability or special educational needs. However, for epilepsy it appears that this does not happen consistently or that individuals often leave the educational system before access to support can be delivered. Some participants stated:

"I had to leave school and did not complete my Leaving Cert".

Individuals with epilepsy should have an ample care plan in place, decided amongst family members and their neurological consultant. It should have primary and secondary care providers. The individual's lifestyle, interests, educational concerns and social adjustments need to be considered also. The educational systems currently place a significant barrier to the successful implementation of the above recommendations from health professions. The unpredictable nature of epilepsy, even if fairly well controlled, often causes stress and recurrent seizures can force absences from education which can result in poorer academic achievements (Besag, 1995). Findings of the present study showed participants faced many missed days in education due to the unpredictable of epilepsy.

"Yes if I have seizures, I miss school, I would have bad headaches"

This coincides with the Chief Executive of Epilepsy Ireland's report, which recognises the lack of effective remedial teachers as an problem area, especially if individuals experience absence seizure or who are regularly absent due to recurrent seizures and without modifications made in the educational environment this could lead to lower education attainment and longer delays in development for individuals. The participants consistently mentioned teachers' lack of knowledge about epilepsy and how clear this was when teachers were faced with experiences of seizures. Participants stated,

"Teachers not knowing what to do with a seizure, being afraid"

This in turn causes high levels of apprehension within a classroom situation. Research findings have suggested that educational organisation were unaware of Epilepsy Ireland until participants informed them and advised them that it was an advisory service providing voluntary support to schools. Epilepsy Ireland (2010) provides teacher packs including information on what is important for a teacher to know about seizures and how to support individuals during their academic journey.

Present findings suggest that the areas with most difficulties were memory, concentration and eye-sight. This is similar to Mc Guire (2016), findings of The Joint Council of Examination Boards in previous studies, when Fenton stated that the memory issue affected keeping up in class and also affected examinations, as *"The Leaving Cert is a memory test, it doesn't define your intelligence but it does define your future",* (Fenton, 2016). An issue facing individuals with epilepsy in the educational environment in secondary level, is the issue of subject exemption and examinations. Participants of the current research stated because,

"My memory and concentration are desperate, I need extra help and my eye sight is terrible, I just can't see things on paper".

At present, Ireland's educational exam system has no circumstances under which a student may sit state exams on a date other than that scheduled on the official timetable, i.e. Junior Cert or Leaving Cert date. The only provisions made by the Department of Education and Science for individuals with epilepsy, is when sitting state examination are as follows: 1) If a seizure occurs during an exam, extra time will not occur to complete the paper but the student will be assessed on the part of the paper which has been completed as if it was a full examination and 2) Provision of a separate room and supervision if requested by the school principal. In order to obtain these two provisions, a student must be aware of them in advance and must apply in November the previous year. A participant stated:

"My Junior Cert, given a room by myself, the teacher told me I had to just go in there, I didn't have a choice"

These provisional arrangements are questionable, as not many schools are aware of the above supports. In secondary education the principal must place the request for a separate room, however in third level education it is the students' choice/role to request this. This could suggest that national and secondary level education environments affect a young person’s abilities and future by removing the individual control and choice around sitting exams in a way that best suits their individual needs.

As a result of previous literature findings the National Council for Curriculum and Assessment (NCCA) acknowledges the necessity for appropriate curriculum guidelines to meet the needs of students with disabilities and learning difficulties. It was further acknowledged through the adaptations to the curriculum and access to it through the use of assistive technology was required. Despite this, the Expert Advisory Group on Certificate Examinations (EAGCE) submitted recommendations to the Department of Education on arrangements for assessments of individuals with special needs stated that

> *“Special arrangements should not put the integrity, reputation or status the examinations at risk”*

This finding is in contrast with Epilepsy Ireland, who states

> “*Where elements have been waived or the method of examining has been considerably altered, this should be indicated by the presence of an explanatory note on the student’s certificate of results*”

Daly (2000) contends that if changes that are made to the current education system to accommodate individuals with special educational needs are such, as to interfere with the integrity of the examination process, a different assessment process should be developed. Previously stated, epilepsy is unpredictable and the pressure and tension of examinations can trigger stress, thus not having the option for extra time or the chance to repeat the full examination could directly influence a young person’s future career. These current findings are reflected in the Department of Equality and Law Reform, (1996) report, on a strategy for equality, in a recent commission statement, which stated, Ireland’s exam system is “*in stark contrast to the position in other countries”, where continuous assessment is more common* (McGuire, 2016). At present, Irelands educational situation, as it stands, is in disagreement with the legislative injunction which the Irish Education Act (1998) places on the educational environments.

Past research has highlighted previous and ongoing provisional discussion between Epilepsy Ireland and the Department of Education and Science about examinations, subject exceptions and bringing in ongoing continuous assessment over a three year period for people with epilepsy as an alternative. This proposal is in line with the current findings, however there remain concerns. In particular, that "if continuous assessment is to be an option to young people with epilepsy, that it will open the floodgates to others" (Murphy, 2016). In difference to the Commission opinion of current findings is Epilepsy Ireland (2010), which state that these measures within the educational environment do not cover the full varieties of difficulties faced by individuals with epilepsy. If a person is absent from an exam due to recurrent seizures before an examination, there is not an option to repeat, unlike third level education, where this option is in place with autumn examinations available.

At present the Department of Education and Science appears not to be in agreement on the concerns regarding examinations and subject exceptions which are essential and applicable to people with epilepsy. Participants stated,

"My school made allowance, the teacher was very good, when I had exams, she'd came into the room that the principal provided"

In contrast,

"The teachers didn't really seem to understand, but I suppose they had no reason to no until I was in the class"

In light of the above, the researcher believes this can lead to the unrecognised levels of potential in students with hidden disabilities, with regards to examinations and subject exceptions. The educational environment has vital role to play in assisting individuals with epilepsy, such as building on much needed self-confidence in order to socialise with other peers and help plan career choices for further education and future employment. Participants expressed concerns regarding future career choices and employment opportunities because of their epilepsy.

"Never got to finish school, I had to change my career because of epilepsy and people not understanding it"

Research findings showed that participants felt that as a consequence of learning disruptions such as concentration, absences due to seizures and hospital appointments, they would require extra assistance with material they missed. Ireland is recognised as one of the countries which is still lacking in the educational provision for students with epilepsy. The current study showed strong indications that individuals who suffer with epilepsy require educational interventions, particularly directed and improved special resource assistance to be delivered.

Comparing the academic supports available within the different educational environments, research suggests that third level, is remotely ahead in providing academic supports for students with epilepsy. Participant stated,

“I can get class-notes taking, that I never got in school”

Findings of the current study showed the educational environments were broadly similar in holding the view that ‘epilepsy is not a recognised condition for special education’. Nonetheless, the fact that the academic supports which are made available to others students with disabilities should be made available to individuals with epilepsy remains crucial, to potentially support future education attainment for all. Disability supports in third level institutes are well-advertised and are available to all individuals equally to help them reach their full education potential, unlike national and secondary level. While this provision within third level is often exceptional, results indicate that without appropriate support at previous levels of the educational system many with epilepsy never gain access to this provision, dropping out or leaving the educational system before they reach this level. Many participants expressed concerns and frustration after having to vacate education, due to academic supports not been accessible, therefore, did not get the opportunity to experience third level education with its appropriate supports.

Epilepsy, as a condition in Ireland, is not recognised and for this reason there is no legislative definition, support or recognition in the educational establishment. Research based on current findings urges the educational system to be on familiar terms with epilepsy as a definite condition and guaranteeing all students equal educational supportive needs.

In regards to epilepsy as a ‘condition’, no reference was made to this in either the Education Act (1998) or the Special Education Review Committee (SERC), (1993) report. If there was recognition, interventions and supports, this would then reflect through injunctions which would be placed on the educational environment by the

Educational Act (1998). According to the Education (Welfare) Act (2000), *“An Act to provide for the entitlement of every child in the state to a certain minimum education, and for that purpose, to provide for the registration of children receiving education in places other than recognised schools, the compulsory attendance of certain children at recognised schools, the establishment of a body, to be known as the National Educational Welfare Board”.* For individuals who suffer with epilepsy and its learning consequences, the Education (Welfare) Act (2000) has vital consequences, for many reasons, such as not receiving any formal education or having to drop out of full-time education. The possibility to change the education system in Ireland within the upcoming period is considered to be a legislative breakthrough states Glendenning (1999).

In schools, the administration of medication for epilepsy is another issue particularly if Buccal Midazolam is required. Besag (1998) states that all that is required following a seizure is time to rest and training is essential to administer medication particularly Buccal Midazolam. This was not borne out in the current findings, which showed that when seizures occurred during school hours, teachers were unaware of what to do and had little knowledge of epilepsy. Participants stated,

“The secretary rang my parents like, asking, what do we do?”

Or

“The teachers were afraid of me, I was always put to the back of the class when a seizure was happening, until someone collected me, I left in the end”

Epilepsy Ireland (2010) uses a desirable technique of educating schools and providers by visiting schools regularly and upon request, providing clear detailed information for teachers and schools. They provide information about the medication aspect of epilepsy including first aid in addition to explaining the effects of epilepsy on the young person and their peers.

Objective Two: To document and analyse the potential barriers faced by these young adults within their educational environment; and to examine their relevant coping strategies.

4.5 Potential barriers faced and challenges within the educational environment

Young sufferers of epilepsy often combine potential barriers and challenges they may face as a challenge. Chung (1995) states problems with epilepsy are not related to seizures but to the misconception or discrimination mainly due to the past beliefs. This has caused difficulties for the individual establishing and maintaining interpersonal relationships. Chung's (1995) theory coincides with findings from the present study which demonstrated participants being unable to retain interpersonal relationships, due to others fear and misunderstanding of their condition, hence causing another barrier in education.

Baker (1997) considers that within the educational environment, people remain surrounded by stigma and this is as challenging as the restrictions forced by the condition or its treatment. Present findings suggested that society causes the young person to feel *"different*" and *"odd"* to others and this along with the side effects of medication like weight gain, facial hair and slurred speech, not to mention the behaviours out of the young person's control such as incontinence, teeth grinding, biting, and foaming from the mouth which are a lot for the individual to deal with and can lead to exclusion and bullying from peers. This concurs with Saraceno, (2005) who states stigmatization that is associated with epilepsy often leads to young people been isolated in education and from society.

Many feel excessive dissatisfaction with the lack of a social life and life events. They feel deprived of meaningful interpersonal relationships (especially with peers) and therefore experience limited social activities. Hani (1996) states the role of the teacher is vital within the management and education of the students with epilepsy, as difficulties come about where there is not enough awareness or coping strategies in place. Hani recommended that in particular, people with photosensitive epilepsy need robust planning for special education. There has to be total avoidance of subjects such as computers as it involves flickering lights. Society needs to consider other aspects which affect the individuals, such as strobe lights and sunlight through trees etc. In regards to society and social activities, individuals with epilepsy become powerless within today’s society and alter their behaviour becoming socially isolated. Social media/Facebook/Snapchat has now become the norm surrounding young adults and the fear of a seizure occurring through the use of PC, tablets and IPhones, is a constant worry. Findings concurred with Hani (1996) as participants stated

> “*Have become more isolated since social media became the norm, it is a waiting game, the fear of the seizure occurring in public”*.

December (2010), Driving legislation came into effect and brought Ireland in line with wider European regulations through the implementation of a European directive. The legislation defines epilepsy as two or more epileptic seizures less than five years apart. Each different seizure type, has a different time frame on it and on how long an individual must be seizure free, before attempting to drive again is set out (Appendix 13 for further in-depth information). Many participants in the current study found this the principal barrier as it challenges employment opportunities and leaves the young person relying on family members, friends or public transport.

Beech (1992) believes that a family’s behaviour, approach and attitude towards adjusting to the condition are moulded by the informed understanding of the disorder. That informed understanding may depend on the professional medical terminology that is used at that time. This is similar to the results of the current study as it indicated a need for more relevant professional communication, and for that to be delivered in a language which is understandable to both the individuals and family members. Similarly, the findings of the study concurs with McGovern (1992) theory, which emphasises that when a young person is diagnosed with epilepsy it is an emotional time for a parent. The parent experiences feelings and reactions of denial, disappointment, depression, and turning to overprotecting a child. The present study agrees with Beech (1992) findings as it showed unanticipated results on how the different age categories can determine how a person copes, understands and manages a diagnoses of epilepsy. Many participants who were 18 years and over but were either born with childhood epilepsy or developed epilepsy at a very young age, when asked about their type of epilepsy and understanding of their own epilepsy, stated*,*

"Mammy knows, she wouldn't let me".

Or

"Parents do my tablets, I'm not allowed".

Restrictions and dependency, long-term care and control specifically placed on an individuals' when diagnosed with epilepsy indicates that epilepsy places a burden on the entire family also. However, previous studies by Rutter et al. (1971) presented evidence that when restrictions and over-protection occurs, individuals becomes considerably dependant on family members, hence not building their own intellectual capacity, self-confidence or independent skills. Similar to findings of the current research, participants who were born or diagnosed from a young age with epilepsy did not have much knowledge about the condition and depended on the family for their medical treatment, educational attainment and social adjustment. This was not the case for participants who were diagnosed at a later stage in life. The response from participants coincides with McGovern (1992) statement on the family reaction to the initial diagnosis of epilepsy in a child. However, Wallace (1994), advises counselling for all family members and individuals who have a history of epilepsy, as many are affected and it can impact on individuals differently. Ward and Bower (1987) suggest that counselling can allow young adults to gain an increased knowledge on their own condition, alongside giving individuals time to educate themselves with regards to the educational supports are that are available. This can facilitate the successful navigation of key social adjustments whilst still facing ongoing challenges relating to the condition. One participant in particular stated

"*No matter what you do, it's never just you with epilepsy, it concerns others and it's always a constant challenge".*

Current findings suggested that epilepsy has an impact on all family members with many reluctant to attend public entertainment, visit family members or relations, go on family holidays, go shopping or even dining in public. Participants stated,

"Family won't let me out of there sight, hate it, we don't go anywhere anymore because of the epilepsy"

Or

“Family hate seizures happening in public”

These are similar findings to Pond, (1991) who states that the risk of disturbance involved, among the individual, overprotective mother/child interactions can also be a forecaster for psychosocial problem for the future.

Merging the literature reviewed and present study results, it is evident that the age at which an individual is diagnosed with epilepsy and the reactions from the family about the initial diagnoses, influence the individual. When a person has been diagnosed with epilepsy from a young age and has an over protective family, there will be restrictions on daily activities. Findings showed that these boundaries can occasionally negatively influence the development of the people with epilepsy and result in delays of personal development and under achievement in education attainment.

4.6 Coping strategies

Receiving a diagnosis of Epilepsy changes the individual’s attitude. Once they overcome the initial diagnosis, they become can become educated on their own condition. This in turn, influences how the individual copes with epilepsy. Jacoby (1996) states that epilepsy has an unfavourable impact on mental health with depression and anxiety being to some extent the problem. This coincides with present findings with many participants developing depression and anxiety after diagnoses. Investigators such as Mc Govern, (1995), highlighted the importance of being in control, knowing your triggers for seizures to be able to prevent them as best possible. It may affect the young person’s self-confidence and self-esteem, a coping strategy used, to achieve control in their lives, was Cognitive Behavioural Therapy (CBT). This focuses on development of active coping strategies thus decreasing seizures and increasing the feeling of control. Jacoby (1996) states young adults are more emotionally better able to adapt because of independent coping methods which are now being developed to help an individual with epilepsy on a day-to-day basis, than in previous years.

4.7 Important supports that should be available

Essential to educational and social attainment is the Epilepsy specialist nurse, whose role involves active listening, education and support on an extensive range of areas such as triggers, medications, driving, lifestyle, education and employment. People with epilepsy, can ring a helpline from all over the country. Epilepsy Ireland community resource officers can be contacted if they have a medical question. Participants stated

This study highlights and previous literature agrees that there is a lack of mental health services for individuals and there is an urgent need for this support to be made available.

The present study suggested a need for the formation of a young adults support group, as at present there is nowhere people can go and meet. Participants stated.

"Like an anonymous group, similar to AA meetings"

This would then contribute to providing information concerning medication, educational, employment needs and mutual support as well as providing a social network for individuals with epilepsy.

4.8 Evaluation of Method and Suggestion for future Research

For the study, a single method which by means of qualitative research approach was designed. This was a semi-structured one-to-one interview, which generated in-depth data. The author used a specific list of questions, relating back to the aims and objectives of the study, in order to ascertain young adult's personal experiences and views on the provisions currently made available to them within the educational system. Integrating a single qualitative method such as semi-structured interviews enabled participants to openly express their views clearly (Rubin & Rubin, 2005, p.4). The use of other qualitative methods could have been used for the same purposes, as on the day of the interviews, participants appeared to share more of their personal experiences while in a group setting than in one-to-one interviews. Patton (2002) believes that a focus groups is a great way to discover people's attitudes, experiences, beliefs and how they behave or which preferences they may have. For this reason, the author would suggest using focus groups, as a more consistent measure to collect data for future studies.

The findings from this research varied due to a diversity of participants in the profile sample. Regrettably, due to epilepsy being such an unpredictable condition and anyone that anyone can receive a diagnosis at any point or time in life, some participants had retrieved a diagnosis once they had left national and secondary level education. The current research group was a diverse group (10 participants), based in a precise location, all of different ages and educational backgrounds. Suggestions for future research is to conduct a longitudinal study, a more ‘focused study’, covering similar age groups and the possibilities of similarities of diagnoses, therefore not such a diverse profile of participants in order to gain a bigger picture and data analysis with this particular research topic.

Summary

In summary, the key themes identified were the initial diagnosis of epilepsy and how it can impact on an individual’s life and career choices enormously, leaving them in state of shock or being overwhelmed. Educational supports lacking for both the individual with epilepsy and all academics within the educational environment, due to ‘epilepsy’ not being recognised under the Education Act (1998) under the term ‘disability’. This in turn, results in student’s education attainment not being of adequate standards and all academics not receiving appropriate training from the Department of Education and teacher training institutions. The findings of the study also gives an insight into potential barriers and challenges faced by young adults such as feeling of inadequacy causing them to feel “different” and “odd” to others because of their epilepsy. In turn, individuals with epilepsy, learn to cope with the condition by devising coping strategies such as regular medication, regular meals, regular sleep, lessen stress when possible, in order to help their epilepsy on a day-to-day basis. Research showed once young people overcome their initial diagnoses and the stigma, individuals are then influenced to become more educated on their own condition and to educate others in society.

Chapter Five

Conclusion

5. CONCLUSION

“Educational difficulties because of epilepsy, are often called the “hidden disability”, as they may not be obvious but can have a significant impact on your behaviour and on daily life.”

(O’ Shafer, 2014, p25)

The purpose of this study was to investigate the possible challenges faced by young adults with epilepsy during their academic journey. Firstly, the research captured an insight into the personal experience of the initial diagnosis and the educational supports available to young people with epilepsy. Secondly, the research carefully measured the potential barriers and challenges faced by young adults within education today, and finally, examined the relevant coping strategies used by young adults.

Jacoby (1996) states that young adults are “more emotionally able to adjust” to epilepsy, especially if they are able to develop independent coping techniques for self-care of their condition. Highlighted throughout previous literature and present research, is the importance of having accurate and distinct ‘knowledge’ about epilepsy.

As a hidden disability, it is especially important to increase awareness and knowledge of the condition across all levels of society. The promotion and creation of an educational and knowledge base to better inform society about epilepsy, will aid the reduction with stigma and stereotypes, whilst providing support to those with epilepsy.

In Ireland, over the last two decades, there has been considerable progress made in increasing awareness and securing the provision of appropriate care for those with epilepsy within the Irish education system. Despite this, Murphy (2016) claims that such progress has been of an ad-hoc nature, and there is an over-all consensus that the services for students with disabilities are in fact, insufficient, both in terms of structure and in delivery. Findings from the present research, conceded there has been little or no change driven by updated policy or legislative provisions. It is notable, that documents and guidelines such as Education Act (1998) or the Special Education Review Committee (SERC), (1993) report, do not specify ‘epilepsy’ by name and refer only to *“some categories of disabilities”*. Findings of current research displayed some several significant insufficiencies in the levels of educational provision for young adults with epilepsy, but also that the academics within these educational environments, are not being provided with appropriate and adequate training in comparison to other countries. Ireland, has no doubt compared to previous years, enhanced awareness of the rights of young adults with special educational needs. This was apparent in the increase of legislation which redressed the current insufficiencies in services for people with disabilities.

Despite the progress made by many individual educational institutions in increasing the provision of care for those with epilepsy, it is not an alternative or a replacement for a consistent policy for young adults with special education needs.

The recommendations developed from this research are regarded to be indispensable to the rights of young people with epilepsy. If epilepsy is not documented or recognised within any educational policy or legislative documents, this leads to further deficits in educational awareness and supports for young adults with epilepsy from national-third level. In turn, resulting in continuing disadvantages for young adults within the education system.

Chapter Six

Recommendations

6. RECOMMENDATIONS

1. The International Bureau for Epilepsy (2013) states that although Epilepsy is not classified as a disability, it is explained as a hidden disability. Hidden disabilities are frequently overlooked or at the very worst demeaned. As suggested ‘Hidden disability’ is sometimes ‘demeaning’, which means that a person’s impairment or condition is not obviously apparent or visible but can cause a severe loss in the dignity and respect for the individual when it does appear.
   For this reason, The Department of Education and Science needs to define epilepsy as a disability under “equity”. This would mean recognising and providing equal rights and entitlements equal to those under the remit of young adults with disabilities and young adults with special educational needs, within all relevant policies and legislation. This will ensure all young people with epilepsy will be provided with special arrangements for circumstances in structured state examinations. An alternative for state examination is the implementation of a repeat date for young people with epilepsy, as seizures triggered by stress and may occur the day of a state examination. An alternative for exemptions of certain subject’s i.e. computers/technology subjects, which may affect some individuals with photosensitive epilepsy or if any young person with epilepsy is to engage long hours, implementation of continuous assessment over a three year period. Then once certain amendments are finalised, they must be vocalised to all concerned.

2. The Department of Education and Science, Epilepsy Ireland and the Teacher Training Institutions, need to work collaboratively in providing and designing a teacher training programme, which focuses on both the educational and medical needs of individuals with epilepsy. This in turn, will raise and improve awareness and knowledge for academics within their roles.

3. Introducing a school medical service, linked with relevant G.P services in conjunction with consent from the individuals and their families, to regularly review prescribed medications and adjusting where necessary. If changes to medication and dosages are required, these changes may be considered (due to side effects and medication changes having possible physical affects) in relation to educational needs during these times to help aid the medication adjustments. It is also important to subsequently monitor the young person levels of attentiveness and behaviour in class throughout the year due to these changes.

4. Raising awareness and knowledge. The school guidance teachers working with Epilepsy Ireland, could provide self-presentation skills and interview techniques for the young person with epilepsy, in order to improve their confidence on how to share and explain the condition to peers, in the event a seizure may occurs during class/social time.

5. Epilepsy Ireland is a voluntary organisation. Government departments should contribute funding towards Epilepsy Ireland, in order to promote awareness of the condition throughout the educational environments. This could be done by incorporating the development and use of visual aids, appropriate technology/computer equipment, suitable teaching materials i.e. more information packs for schools.

6. Providing the designated counselling services and support groups should be an integral part of the medical programme delivered by health care services. The delays could be decreased by using the services of the Epilepsy Special Nurse as opposed to consultants, to avoid long waiting list. Onward referrals must not to be delayed. Once diagnosed, all individuals and their families should be made immediately aware of Epilepsy Ireland and the relevant support groups.

References

7. REFERENCE LIST

Amaro, O. (1995). *Prevention Program Evaluation Report*. Prepared for the Massachusetts Primary Prevention Group and the Massachusetts Department of Public Health.

Anderson, C. J. K., Klassen, R. M., & Georgiou, G. K. (2007). Inclusion in Australia: *What teachers say they need and what school psychologists can offer*. School Psychology International, *28* (2), pp. 131-147.

Athlone Institute of Technology (2012). *Child Protection Policy and Procedures*. Athlone: Athlone Institute of Technology.

Bagel, C. (1972). Social prejudice and the adjustment of people with epilepsy. *Epilepsia* 13: 33-45.

Baker GA, (1997). The International Bureau for Epilepsy. Perceived impact of epilepsy in teenagers and young adults: An international survey. Epilepsy and Behaviour; 12(3):395–401.

Barbour, R. (2008). Interviewing and Focus Groups. In: Lewin, B.C (eds.) *Research Methods in the Social Sciences* (pp. 41-48). London: Sage.

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

Baumann, R.J, Wilson, J.E and Wiese, H.J (1995). Kentuckians' attitudes towards people with epilepsy. *Epilepsia* 36: 1003-8.

Beech, L. (1992). Knowledge of epilepsy among relatives of the epilepsy sufferer. *Seizures* 1: 133-135.

Besag F. M. C (1994). Epilepsy, education and the role of mental handicap. In *Epilepsy and Education,* Vol. 2, No. 3: 561-583, (Eds Ross E.M and Woody R.C) Bailliere’s Clinical Paediatrics International Practice and Research.

Besag F. M. C (1995). Epilepsy, Learning and behaviour in childhood. *Epilepsia,* 36 (**Suppl**. 1):S58-S63.

Besag F.M.C (1998). Special education participation in children with epilepsy: What does it reflect? *Epilepsy and Behaviour*; 22(2):336–341.

Bishop M, Boag EM. (2006). Teachers' knowledge about epilepsy and attitudes toward students with epilepsy: Results of a national survey. *Epilepsy and Behaviour*. 8(2):397–405.

Bowling A. (2002). Research Methods in Health, *Investigating Health and Health Services,* 2nd ed. Open University Press, Buckingham.

Brainwave, The Irish Epilepsy Association (1991). *A Teacher’s Guide,* (Information Pack).

Brainwave, The Irish Epilepsy Association (1992). *Explaining Epilepsy*, (Information Booklet)

Brainwave, The Irish Epilepsy Association (1992). *Questions and Answers,* (Information Booklet)

Brainwave, The Irish Epilepsy Association (1992). *Seizures,* (Information Booklet)

Brainwave, The Irish Epilepsy Association (1998). Special exams considerations for state examination In; *Epilepsy News*. The Irish Epilepsy Association.

Brainwave, The Irish Epilepsy Association (2000). *The Doctor's Pack*, (Information Booklet)

Britten N, (2006). Evaluating meta-ethnography: *a mixture of qualitative research.* Social Science Med. 2003, 56: 671-684. 10.1016/S0277-9536(02)00064-3.

Browne, T.R (2011). Antiepileptic drugs and psychosocial development: Ethosuximide. In: *Antiepileptic drugs therapy in Paediatrics* (Eds. Morselli, P.L, Pippenger and Penry, J.K) raven Press, New York, Pp. 181-187.

Bryman, A. (2004). *Social research method*. New York: Oxford Press.

Bryman, A. (2008). *Social research methods*, (4th Ed.). Oxford: Oxford University Press.

Caveness, W.E and Gallup, G.S (1998). A survey of public attitudes towards epilepsy in 19997 with an indication of trends over the last thirty years. *Epilepisa*. 21: 509-18.

Chung M.Y (1995). Survey of public awareness, understanding and attitudes towards epilepsy worldwide. *Epilepsia*, 36 (5): 488-493.

Commission for the Control of Epilepsy and its Consequences, (1978). *Plan for Nationwide Action on Epilepsy,* Vol. II DHEW Publication no. 78-279. Bethesda, MD.

Daly, T. (2000). Context and assistive technology in Irish mainstream education. A paper presented at a conference on *Human factors in Delivering an Assistive Technology Service: from Local to Global.* Central Remedial Clinic, Dublin. (Publication pending).

Daymon, C., & Holloway, I. (2011). *Qualitative research methods in public relations and marketing communications.* Abingdon: Routledge.

De Boer, H.M (1995). Epilepsy and Society. *Epilepsia* 36 (**Suppl**. 1): S8-S11.

Denzin, N.K & Lincoln, Y.S (2000). *Handbook of Qualitative Research* (2nd ED.). Thousand Oaks, California: Sage.

Department of Children and Youth Affairs (2011). *Children First: National Guidance for the Protection and Welfare of Children*. Dublin: Government Publications. Available at www.dcya.gov.ie [accessed January/2016].

Department of Children and Youth Affairs (2012). *Guidance for Developing Ethical Research Projects involving Children*. Dublin: Department of Children and Youth Affairs. Available at www.dcya.gov.ie [accessed January/2016].

Department of Education and Science, Ireland (1999). Special Educational Needs: *Curriculum Issues*, Discussion Paper. National Council for Curriculum and Assessment. Dublin: S.O.

Department of Education and Science, Ireland (1999). Task Force on Dyslexia and Autism.

Department of Education and Science, Ireland (2000). *The Chief Executive reports on special education needs to the Minister for Education and Science.* Dublin. S.O.

Department of Education and Science, Ireland (2000). *The report of the expert advisory group on certificate examination (2000)*. Arrangements for the assessment of candidates with special needs in certificate examinations. Report to the Minister for Education and Science. Dublin. S.O.

Egg-Olofsson, O. (1990). Basic principles of the classification of epileptic seizures and syndromes. In *Paediatric Epilepsy* (Eds. Sillanpaa, M., Johanessen, S.I., Blennow, G., and Dam, M) Wrightson Biomedical Publishing Ltd.

Epilepsy association of U.K. (2016). *My seizure plan.* (Information Booklet). www.epilepsyassociation.com [accessed 22/05/2016].

Epilepsy Ireland (1998). Educational needs or requirements for young people in Ireland in: *Epilepsy News*. The Epilepsy Association.

Epilepsy Ireland (2010). Figures and prevalence on Epilepsy in Ireland in: *Epilepsy News*. The Epilepsy Association.

Epilepsy Ireland (2015). The Irish Epilepsy Association, First Aid guide on types of Seizures, (Information Booklet). www.epilepsyireland.ie [accessed 12/05/2016].

Fastenau P., Shen, J., (2008). *Academic underachievement among children with epilepsy: proportion exceeding psychometric criteria for learning disability and associated risk factors.* 41(3):195-207. Doi: 10.1177/0022219408317548.

Fenwick P. (1996). The behavioural treatment of epilepsy generation and inhibition of seizures. *Journal of Neuro Clinic*. Feb; 12(1):175–202.

Fenwick, P. (2014). Evoked and psychogenic seizures: Precipitation. *Actual Neurol*. Scand. 80, 541-547.

Fisher RS, (2005). *“Epileptic seizures and epilepsy”,* Definitions proposed by the International League against Epilepsy (ILAE) and the International Bureau for Epilepsy (IBE). (2013) *Epilepsies*, 46:470–472.

Fisher, R.S., (2005). "The impact of epilepsy from the patient's perspective. Descriptions and subjective perception." *Epilepsy Research* 41: 39 - 51

Frieden, T.R., (2010). *“Epilepsy in adults and access to care--United States”, Centre for disease control and prevention MMWR.* Morbidity and mortality weekly report, 2012. 61(45): Pp. 909

Glendenning, D. (1999). *Education and the law*. Butterworths (Ireland) ltd.
Gordon, N. and Sillanpaa, M. (1997) Epilepsy and prejudice with particular relevance to childhood and adolescences. *Developmental Medicine and Child Neurology*, 39: 777-781.

Hani R, (1996). Teachers' perceptions of epilepsy. *Archives of Disease in Childhood*. 67(12):1467–1471

Hand. M and Hillyard. S, (2014). Big Data? Qualitative Approaches to Digital Research, in Martin Hand, Sam Hillyard (eds.) *Big Data? Qualitative Approaches to Digital Research* (Studies in Qualitative Methodology, Volume 13) Emerald Group Publishing Limited.

Hassed, C. (1996). Meditation in general practice. Australian Family Physician: *Journal of Resting the mind*, 25: 1257–1260.
Heinemann Ltd.

Holliday, A. R. (2007). *Doing and Writing Qualitative Research*, P. 6, Newbury Park: Sage.

Ireland (1983). The education and training of severely mentally handicapped children in Ireland. Report of working party to the Minister of education and the Minister of Health and Social Welfare. Dublin, S.O

Ireland (1993). Report of the Special Education Review Committee: Dublin, S.O

Ireland (1996). A Strategy for Equality: Report of the Commission on the Status of People with Disabilities. Dublin: Department of Equality and Law Reform.

Ireland (1996). Constitution Review Group. Dublin S.O.

Ireland (1998). Education Act. Dublin S.O.

Ireland (1998). Education Act. In: *Section 21 (1); The needs of students who have a disability and the educational needs of exceptionally able students*. Dublin S.O.

Ireland (1999). National Disability Authority Act. Dublin S.O.

Ireland (2000). Education (Welfare) Act. Dublin S.O.

Ireland (2000). Equal Status Act. Dublin S.O.

Ireland (2000). National Council for Curriculum and Assessment (NCCA), *Curriculum Guidelines*, Department of Education and Science, Dublin S.O.

Jacoby A, (1996). The clinical course of epilepsy and its psychosocial correlates: Findings from a UK community study. *Epilepsia.* 37(2):148–161.

Jacoby A, Baker G.A. (2008). 'Quality-of-life trajectories in epilepsy: A review of the literature'. *Epilepsy and Behaviour*. 12(4):557–571

Jacoby, A. (1996). Epilepsy and the quality of everyday life: findings from a study of people with well-controlled epilepsy; Social Science and Medicine 34(6): 657-666.

Joint Epilepsy Council (2011). Epilepsy prevalence, incidence and other statistics; available from: http://www.jointepilepsycouncil.org.uk/downloads/Epilepsy%20Prevalence,%20Incidence%20and%20Other%20Statistics.pdf [accessed 05. February. 2016.]

Kean, R. (2004). *Bringing epilepsy out of the shadows*. BMJ, 315 (70099) 2-3.

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

Marcon, R.A. (1999). *Positive relationships between parent school involvement and public school inner-city preschoolers' development and academic performance.* School Psychology Review, 28 (3), 395-412

May TW, Pfäfflin M. (2002). The efficacy of an educational treatment program for patients with epilepsy (MOSES): results of a controlled, randomized study. Modular Service Package Epilepsy. *Epilepsies;* 43:539–49

Mc Guire. P (2016). Epilepsy and the Leaving Cert: *'If it strikes, that exam is over for me',* Irish times newspaper, accessed from: http://www.irishtimes.com/news/education/epilepsy-and-the-leaving-cert-if-it-strikes-that-exam-is-over-for-me-1.2593487 [accessed on 5th April/2016].

McGovern, E.A (1992). The impact of a new paediatric epilepsy diagnosis on parents: Stress and activity patterns. *Epilepsy and Behaviour*. 14(1):237–242

McGovern, E.A (1995). The incidence of first provoked and unprovoked seizure in paediatric patients with and without psychiatric diagnoses. *Epilepsia.* 48(6):1075–1082.

Murphy P. (2016). Epilepsy and the Leaving Cert: *'If it strikes, that exam is over for me', Irish times newspaper,* accessed from: http://www.irishtimes.com/news/education/epilepsy-and-the-leaving-cert-if-it-strikes-that-exam-is-over-for-me-1.2593487 [accessed on 5th /April/2016].

O' Donohue, N.V (1994). *Epilepsies of Childhood research*, Butterworth-

O' Shafer RN. (2014) Epilepsy across the Spectrum: Promoting health and understanding – *an IOM Report on Epilepsy, much can be done to improve the lives of people with epilepsy*, 24, (2), p25.

Oosterhuis A. (1999). Coping with epilepsy: *the effect of coping styles on self-perceived seizure severity and psychological complaints*. Seizure. 8:93–96. doi: 10.1053/seiz.1998.0255.

Palys, J (2008). Purposive sampling. In L. M. Given (Ed.) *The Sage Encyclopedia of Qualitative Research Methods.* (Vol.2). Sage: Los Angeles, pp. 697-698.

Patton, M. Q. (2002). *Qualitative research & evaluation methods* (3rd ed.). Thousand Oaks, CA: Sage.

Pond, D (1991). Psycho-social aspects of epilepsy- the family. *In Epilepsy and Psychiatry* (Trimble, M.R and Reynolds, E.H) Churchill Livingstone.

Pond, H. (1981). Parental attitudes towards children and young adults with chronic medical disorders: special reference to epilepsy and diabetes mellitus. *Diabetes Care* 2:425-431.

Riessman, C.K. (1993). *Narrative Analysis*. P.34, California: Sage.

Road Safety Authority, (2010). Driving Regulations: *2010 Driving Legislation*, accessed from http://www.rsa.ie/RSA/Licensed-Drivers/Safe-driving/Medical-Issues [Accessed on 13/04/2016].

Rogers, C. (1961). Opinions about accommodating employees with chronic illnesses. *Journal of Applied Rehabilitation Counselling*. 28(3):29–34.

Ross, E.M, and Tookey, P. (1988). Educational needs and epilepsy in childhood. In: *Epilepsy behaviour and cognitive function* (Eds Trimble M.R and Reynolds E.H, 1981). John Wiley and son's ltd.

Rubin, H. J., and. Rubin, I. S. (2005). Qualitative Interviewing – The Art of Hearing Data. 2nd Edition, P.4, Sage Publications, Thousand Oaks, London, New York.

Rutter, M., Graham, P. and Yule, W. (1971). A neuropsychiatric study in childhood. *Clinics in Development Medicine*, Nos 35-36. Spastics International/Heinemann Medical, London.

Saraceno, B. (2005). A qualitative study exploring how children and adolescents view the impact of intractable epilepsy on their quality of life. *Epilepsy and Behaviour* :(4):664–678

Sarantakos, S. (1998). Social Research. (2nd Ed). China: Macmillan Publishers.

Shargel, L, (2000). *“Comprehensive pharmacy Review for NAPLEX”,* 8th Edition. Eds, Wolters Kluwer/ Lippincott Williams & Wilkinson, pp743.

Sillanpaa, M. (1992). Epilepsy in young adults: Prevalence, disability and handicap, *Epilepsia* 33 (3), 444-449.

The International Bureau for Epilepsy (IBE), (2013). IBE Newsletter, European Regional Committee, *Journal to promote higher quality and safety of care.* Issue 1, Vol 2, Pp 2-13.

The Joint Council of Examination Boards (JCEB), (2008). Ireland and England, special educational requirements: Curriculum issues. *Journal of Discussion. Joint Council for Assessment and Curriculum,* Dublin: S.O.

Trimble, E.H and Reynolds, M.R (1981). Epilepsy and Psychiatry. Churchill Livingstone, Edinburgh.

Wallace, S. (1994). Practical problem of epilepsy management in children and young adults. *Seizures*, 3: 177-182.

Ward, F and Bower, B.D. (1978). A study of certain social aspects of epilepsy in childhood and young adults. *Developmental Medicine and Child Neuro,* Supply. 39. Vol. 20, No. 1.

Wong J and Wirral E. (2006). Physical activity in children/teens with epilepsy compared with that in their siblings without epilepsy. *Journal of Epilepsia*; 47(3):631-9.

Zaslow, M. J and Takanishi, R. (1993). Priorities on for research on adolescence development*, America Psychologist*, 48, 185-192.

Appendices

8. APPENDICES

APPENDIX 1: Letter to head of school, Business & Social Sciences

Institiúid Teicneolaíochta Bhaile Átha Luain
Athlone Institute of Technology

37 Parnell Square
Athlone
Co. Westmeath
087-9459150

Dr. Perry Share
Head of School of
Business & Social Sciences,
Institute of Technology, Sligo
Date: 12/02/2016

Dear Dr. Share,

I would first like to introduce myself, my name is Gillian Mc Ardle, and I completed the '*Training for Success'* course in IT Sligo in 2005. I have moved on to furthering my education by obtaining my Honors degree in Applied Social Care in AIT.
I am presently undertaking my Masters in Child and Youth Studies in Athlone Institute of Technology. I have chosen to research the topic of epilepsy and the experiences of young adults with epilepsy in education.
I am seeking permission from you as the Head of school and also the course manager, of Training for Success in the Institute of Technology, Sligo to conduct qualitative research in the form of structured interviews with a number of students attending the current Training for Success course.
The individual interviews will last no longer than 30 minutes. I will be gathering information relating to the main aim and objectives of my research which are as follows: insight into their initial diagnosis, educational supports which were available, potential barriers faced by these participants along their academic journey and identifying some of their coping strategies. I will inform all participants that the decision to get involved is on a voluntary basis, and if they agree to take part, they can withdraw from participating at any time. The information will be treated with the strictest level of confidentiality. Participants will not be identified or names will not be presented in my study. All information gathered will be for the sole purpose of my fulfilling my masters. My supervisor name is Ms. Pearl Moore, who is contactable at pmoore@ait.ie

If permission is granted I would appreciate if I could receive this permission by written correspondence, which will be supplied to the ethics committee at Athlone Institute of Technology, along with my ethics application form.
Yours sincerely,

____
Gillian Mc Ardle
gillian.mcardle@hotmail.com

APPENDIX 2: Letter to ‘Training for Success’ programme, course manager

37 Parnell Square
Athlone
Co. Westmeath
087-9459150

Dear Honor,

As you are aware I completed the ‘*Training for Success’* course in 2005 and I have moved on to furthering my education by obtaining my Honors degree in Applied Social Care in AIT.

I am presently undertaking my Masters in Child and Youth Studies in Athlone Institute of Technology. I have chosen to research the topic of epilepsy and the experiences of young adults with epilepsy in education.

I am seeking permission from you as course manager and also the Head of school, Sligo Institute of Technology, to conduct qualitative research in the form of structured interviews with a number of students attending the current Training for Success course.

The individual interviews will last no longer than 30 minutes. I will be gathering information relating to the main aim and objectives of my research which are as follows: insight into their initial diagnosis, educational supports which were available, potential barriers faced by these participants along their academic journey and identifying some of their coping strategies. I will inform all participants that the decision to get involved is on a voluntary basis, and if they agree to take part, they can withdraw from participating at any time. The information will be treated with the strictest level of confidentiality. Participants will not be identified or names will not be presented in my study. All information gathered will be for the sole purpose of my fulfilling my masters. My supervisor name is Ms. Pearl Moore, who is contactable at pmoore@ait.ie

If permission is granted I would appreciate if I could receive this permission by written correspondence, which will be supplied to the ethics committee at Athlone Institute of Technology, along with my ethics application form.

Yours sincerely,

Gillian Mc Ardle
gillian.mcardle@hotmail.com

epilepsy Ireland

Head Office:
249 Crumlin Road, Dublin 12
Tel: 01 4557500; Fax: 01 4557013
Email: info@epilepsy.ie; Web: www.epilepsy.ie

Winning Project STAR AWARDS 2013

Training For Success:
Institute of Technology, Ash Lane, Sligo.
Tel: 071 9155303
Email: broderick.honor@itsligo.ie or
tansey.maire@itsligo.ie

Ms. Gillian McArdle
37 Parnell Square
Athlone
Co Westmeath

29/01/2016

Dear Gillian

I acknowledge your request, to conduct qualitative research in the form of structured interviews with students attending the current Training for Success course. I as Course manager grant you that permission on the basis that they give their fully informed consent according to the ethical guidelines required for such research.

Yours sincerely

Honor Broderick

Honor Broderick

Course manager

Epilepsy Ireland is the trading name of Brainwave - The Irish Epilepsy Association.
Company limited by guarantee. Registered in Dublin 77588. Registered CHY No: 6170.
Registered Office: 249 Crumlin Road, Dublin 12
Directors: C. Crehan Dowdall, T. Dagge (British), Dr. N. Delanty, M. Dowdall, Dr. M. Hennessy, Dr. B. Lynch, M. McCahill,
Dr. B. McNamara, N. Mitchell, A. Muddiman, C. Saarsteiner, V. Savino, Dr. J. Senior, Dr. B. J. Sweeney, Dr. D. Webb.

APPENDIX 3: <u>Letter of response, approving the research</u>

APPENDIX 4: Information sheet

Information Sheet

Date:

Epilepsy, a hidden disability

Dear Participant:

I would like to introduce myself, my name is Gillian Mc Ardle. I'm undertaking a Masters in Child and Youth Care in Athlone Institute of Technology. The purpose of my study is to create an awareness about epilepsy, and to investigate the possible challenges faced by young adults with epilepsy, during their academic journey.

If you agree to participate in my research study I will include you as one of my interviewee's. An interview will take place at a late date. The interview will be a structured interview to enable me to gather information for my dissertation in order to create awareness of the condition. I will forward the questions prior to the interview.

The interview will last approximately 30 minutes. I will be gathering information on the following: insight into your personal experience of initial diagnosis, educational supports available to you, potential barriers faced by you within your educational environment, and some of your relevant coping strategies.
Participation is voluntary, if you do agree to take part, you can withdraw at any time. If you do take part, the information will be treated with the strictest level of confidentiality. Your name will not be presented in my study, pseudo names will be used in their place.

For the interview, I will seek your permission to audio record to ensure that I gather all the data accurately. If you do not want to use this method, I will record what you say in writing. If you agree to participate and become uncomfortable at any time during the process, you can stop the interview at any time.

If you have any questions in regards to the study, please contact me on **087-9459150**.
I have attached a consent form, consent for participation and for the interview to be recorded. If you agree to participate, please sign the consent form attached.
Thank you for taking the time to read the above information sheet.

Kindest Regards,

APPENDIX 5: Letter of consent for interviews

Institiúid Teicneolaíochta
Bhaile Átha Luain
Athlone Institute
of Technology

Consent Form:

I agree to voluntarily take part in the research study carried out by Gillian Mc Ardle on the topic of Epilepsy, a hidden disability. I am agreeing to participate in the study and I am aware that the data obtained will be for the sole purpose of this research and at no time will I be identified within the research. I fully understand that I can change my mind and withdraw from the study at any time.

1. Are you 18 years of age or over? Yes ☐ No ☐
2. If you feel more comfortable with a third party present during the interview please tick the box. Yes ☐ No ☐
3. Do you consent to have the interview audio recorded? Yes ☐ No ☐

I hereby certify that I have read the foregoing and fully understand the meaning and effects thereof, sign below.

Please Sign Your Name Here: ________________________________

Please Print Your Name Here: ________________________________

Today's Date: ________________________________

APPENDIX 6: List of interview questions

List of Interview Questions

Objective One

1. What age are you and at what age did you develop Epilepsy?
2. How did you feel when you knew or realised you had your first seizure and then were finally diagnosed with epilepsy?
3. It has been said that there is over 40 different types of seizures, have you been diagnosed with any one particular type?
4. Has medication prescribed for your epilepsy affected you in any way with your education?
5. What supports were given to you with regards to your epilepsy, to the management of seizures and administration of medication? (If medication had to be taken during school hours)

Objective Two

6. What are the main challenges faced by you living with epilepsy within your personal life?
7. Was there educational supports available if you attended national and secondary school?
8. What educational supports are available to you now in third level education?
9. Was there any potential barriers faced by you within the educational system now and over previous years?
10. Have you missed many days from school over the years due to your condition?
11. As a person dealing with a condition on a day-today basis, what are your coping strategies for both yourself and the condition?
12. What impact if any, has your epilepsy in your opinion had on your personal, social life and academic life?

13. Is there any other supports that you feel should be available for people with epilepsy?

APPENDIX 7: Interview schedule

Interview Schedule

Name: Gillian Mc Ardle Date: 18/04/2016

Course: M.A in Child and Youth Studies

Location: Institute of Technology Sligo

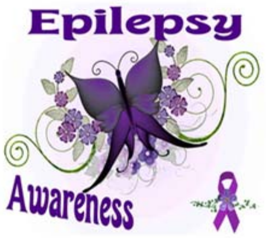
Start Time	**End Time**	**Name of Participant/ Pseudo Name used for study**
1.		
2.		
3.		
4.		
5.		
6.		
7.		
8.		
9.		
10.		

Interview times maybe shorter but will not exceed 40 minutes.

APPENDIX 8: Information leaflet of services available

Support and Services available to students

Useful Contact Numbers



Student Counsellor - 071-9305542

Counsellor: Dr. Siobhan McNally D Cons Psych, MSc, BA

Opening Hours: Monday to Friday 9.00am to 4.00pm

Student Counselling Service at Institute of Technology, Sligo. We are located in the ground floor of the Student Centre, beside the Students Union.
Each day this services has an emergency appointment at 3pm, so do feel free to drop in. You do not need to have appointments. Siobhan is always available to students who may have something on their mind.

- Student Health Service - Nurse 071-9305205
- Student Health Service – 071-9305463
- Student Services/ Students Union 071-9137369/071-9141887

- Epilepsy Ireland 01 455 7500
- Epilepsy Ireland, North West - Regions Covering: Donegal, Leitrim & Sligo. 074 9168725
- Office hours Monday, Tuesday and Wednesday 9am- 5pm and Thursday 9am- 1pm.
- Specialist Epilepsy Nurse Helpline 01 455 4133

Out of Hours Supports:

Your own GP

Sligo General Hospital Emergency Department - 071 9174504

IT Sligo Garda Liaison -071 9157000

Sligo Garda Station - 071 915700/9142031

IT Sligo Security - 087 6379470

The Samaritans - 116 123

APPENDIX 9: Classification and different types of epilepsy

Seizures fall into two categories:	
Focal/partial seizures and Primary Generalised seizures – The difference between these types is how they begin. Focal/partial seizures start in one part of the brain (that is at a focal point in the brain) and affect that part of the body controlled by that part of the brain	
Focal/partial seizures include:	
Simple partial seizures	Which are localised seizures, affecting only one part of the brain. The symptoms the person experiences will depend on the function that part of the brain controls. The seizure may involve the involuntary movement or stiffening of a limb, feelings of déjà vu, an unpleasant smell or taste, or sensations in the stomach such as ‘butterflies’ or nausea. The person remains alert throughout the seizure and can remember what happens. The seizure usually lasts less than two minutes. A simple partial seizure can progress to a complex partial seizure and/or a secondarily generalised seizure. These are commonly referred to as auras.
Complex partial seizures	Affects only one part of the brain but the person’s conscious state is altered rather than lost. The person may often appear confused and dazed and may do strange and repetitive actions like

	fiddling with their clothes, making chewing movements or uttering unusual sounds. These behaviours may also be described as trance-like or robot-like and are called automatisms. The seizure usually lasts for one to two minutes but the person may be confused and drowsy for some minutes to several hours afterwards and have no memory of the seizure or the events just before or after it. This type of seizure can be mistaken for drug/alcohol-affected behaviour or psychiatric disturbance. At times complex partial seizures can spread to become secondarily generalised seizures.
Primary Generalised seizures involve the whole brain. There are many types of generalised seizures, some convulsive, others non-convulsive. Convulsions involve rapid and repeated contraction and relaxation of muscles resulting in uncontrolled shaking of the body	
Primary Generalised seizures include:	
Tonic Clonic seizures	There is a general stiffening of muscles without jerking. The person may fall to the ground if standing.
Atonic seizures	where there is a sudden loss of muscle tone and a collapse to the ground (also known as "drop attacks")
Myoclonic seizures	Which abrupt jerking of the limbs occurs. These often happen within a short time of waking up.
Absence Seizures	There is a brief interruption of consciousness without any obvious signs. These occur most commonly in

	youths and used to be known as "petit mal" epilepsy
*(Fisher 2005, cited in the International Bureau for Epilepsy (IBE), 2013)	

APPENDIX 10: First Aid for Epilepsy/Complex partial seizures

First Aid for Complex Partial (focal) seizures

including temporal lobe seizures

Non-convulsive seizures in which awareness is affected but consciousness is not lost

KNOW THE SIGNS

Wandering aimlessly

Fidgeting with clothing

Agitated behaviour

Chewing & smacking of lips

Confused or slurred speech

Staring trance-like

KNOW WHAT TO DO

DO time the seizure

DON'T restrain or grab

DO guide gently from danger

DO calmly reassure

DO stay until seizure ends

DO explain what happened

When to call an ambulance

- *If the seizure is longer than 5 minutes*
- *If the person has more than one seizure*
- *If you know it is the person's first seizure*
- *If the person is injured*
- *If you are in any doubt*

Epilepsy Ireland

249 Crumlin Road, Dublin 12.
T: 01 4557500. info@epilepsy.ie
www.epilepsy.ie
facebook.com/epilepsy.ie
@epilepsyireland

Epilepsy Ireland (2015) www.epilepsyireland.ie

APPENDIX 11: First Aid for Epilepsy/Tonic Clonic seizures

First Aid For Tonic Clonic Seizures

Convulsive seizures where the body stiffens (tonic phase) followed by general muscle jerking (clonic phase)

1. DO time the seizure
2. DO remove any harmful objects
3. DO cushion the head
4. DO look for Epilepsy I.D.
5. DON'T put anything in the person's mouth
6. DON'T restrain the person or move unless in danger
7. DO turn the person on side (into recovery position) when seizure stops
8. DO stay with the person until the seizure ends and offer assistance

When to call an ambulance

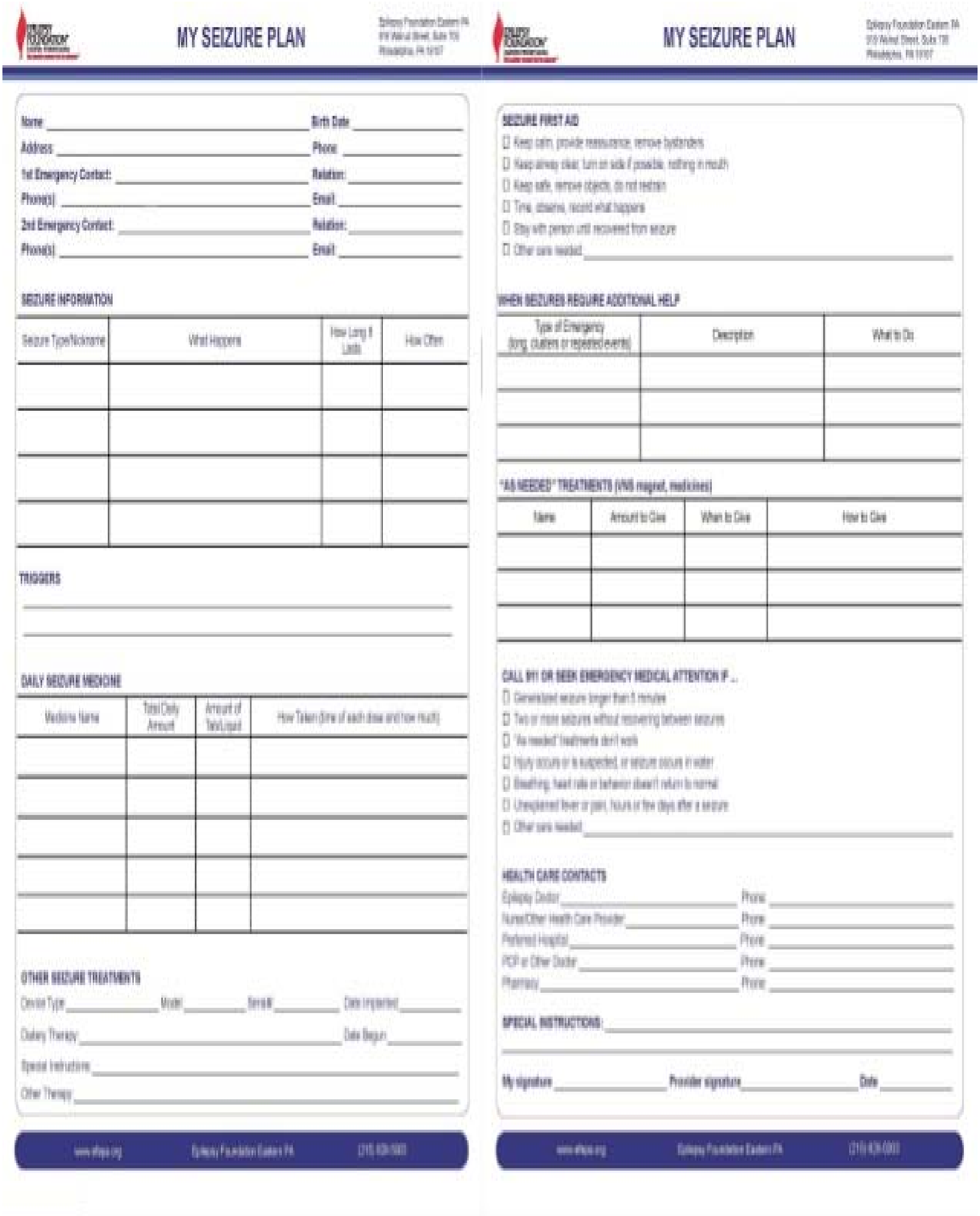
- If the seizure is longer than 5 minutes
- If one seizure follows another without stopping
- If you know it is the person's first seizure
- If the person is injured
- If you are in any doubt

Complex Partial Seizures

Epilepsy Ireland

Epilepsy Ireland (2015) www.epilepsyireland.ie

APPENDIX 12: Files which should be in each school worldwide - awareness of my seizure plan



MY SEIZURE PLAN

Epilepsy Foundation Eastern PA

Name ____________________ Birth Date __________
Address ____________________ Phone __________
1st Emergency Contact: ____________________ Relation: __________
Phone(s) ____________________ Email __________
2nd Emergency Contact: ____________________ Relation: __________
Phone(s) ____________________ Email __________

SEIZURE INFORMATION

Seizure Type/Nickname	What Happens	How Long It Lasts	How Often

TRIGGERS

DAILY SEIZURE MEDICINE

Medicine Name	Total Daily Amount	Amount of Tab/Liquid	How Taken (time of each dose and how much)

OTHER SEIZURE TREATMENTS

Device Type __________ Model __________ Serial # __________ Date Implanted __________
Dietary Therapy ____________________ Date Began __________
Special Instructions ____________________
Other Therapy ____________________

www.efepa.org Epilepsy Foundation Eastern PA

MY SEIZURE PLAN

Epilepsy Foundation Eastern PA

SEIZURE FIRST AID

- ☐ Keep calm, provide reassurance, remove bystanders
- ☐ Keep airway clear, turn on side if possible, nothing in mouth
- ☐ Keep safe, remove objects, do not restrain
- ☐ Time, observe, record what happens
- ☐ Stay with person until recovered from seizure
- ☐ Other care needed ____________________

WHEN SEIZURES REQUIRE ADDITIONAL HELP

Type of Emergency (long, clusters or repeated events)	Description	What to Do

"AS NEEDED" TREATMENTS (VNS magnet, medicines)

Name	Amount to Give	When to Give	How to Give

CALL 911 OR SEEK EMERGENCY MEDICAL ATTENTION IF ...

- ☐ Generalized seizure longer than 5 minutes
- ☐ Two or more seizures without recovering between seizures
- ☐ "As needed" treatments don't work
- ☐ Injury occurs or is suspected, or seizure occurs in water
- ☐ Breathing, heart rate or behavior doesn't return to normal
- ☐ Unexplained fever or pain, hours or few days after a seizure
- ☐ Other care needed ____________________

HEALTH CARE CONTACTS

Epilepsy Doctor ____________________ Phone __________
Nurse/Other Health Care Provider ____________________ Phone __________
Preferred Hospital ____________________ Phone __________
PCP or Other Doctor ____________________ Phone __________
Pharmacy ____________________ Phone __________

SPECIAL INSTRUCTIONS ____________________

My signature __________ **Provider signature** __________ **Date** __________

www.efepa.org Epilepsy Foundation Eastern PA

Epilepsy association of U.K. (2016) www.epilepsyassociation.com

APPENDIX 13: 2010 summary of driving regulations in respect of epilepsy

Group 1: Cars, Light Vans and Motorcycles
The main seizure freedom period for personal driving in categories A1, A, B, EB, M or W (car light van or motorcycle) remains the same at one year of seizure freedom.
Provoked seizures: a person who has had a provoked epileptic seizure due to a recognizable provoking factor that is unlikely to recur at the wheel may be declared able to drive on an individual basis subject to neurological opinion. (Previously six months)
Sleep seizures: For persons who have seizures exclusively in sleep they may be declared fit to drive once this pattern has been established for no less than one year. (Previously 2 years). If a further occurrence of a seizure happens in waking a one year seizure freedom period is required.
Seizures without influence on consciousness or the ability to act - persons with who have never had any seizures other than seizures which have been demonstrated to affect neither consciousness nor cause any functional impairment can be declared fit to drive once this pattern has been established for no less than one year (was previously subject to neurological opinion). If there is an occurrence of any other kind of seizure then a one year seizure freedom period is required.
Initial or isolated seizures: a person who has had an initial seizure or loss of consciousness should be advised not to drive and a specialist report is required regarding the period of driving prohibition and follow up to be undertaken.
First or single unprovoked seizures: a person who has had a first unprovoked epileptic seizure may be declared fit to drive after a period of six months seizure freedom with an appropriate medical assessment preferably a Neurological assessment.
Seizures associated with a physician directed change or reduction of anti-epileptic therapy: in such cases the person may be advised not to drive from the beginning of the period of withdrawal and for six months after stopping of treatment. Seizures which occur during the physician advised change or withdrawal of medication require three months off driving if previously effective treatment is reinstated.

Surgery: In cases where a person has had curative epilepsy surgery the seizure freedom period prior to licencing is the same as the main seizure freedom period for epilepsy i.e.1 year.

The new regulations provide definitions of epilepsy and provoked seizures:

Epilepsy: common medical disorder characterised by recurrent seizures....as defined by having had 2 or more epileptic seizures less than five years apart.

Provoked epileptic seizure: seizure which has a recognisable causative factor that is avoidable.

The new regulations state that all drivers with epilepsy should be under annual licence review until they have been seizure free for a period of at least five years.

Persons with epilepsy will not meet the criteria for unconditional licencing (10 year licence) and notification should be given to the licensing authority.

Group 2: Lorries, Buses, Heavy Goods Vehicles **-** In the case of applicants with epilepsy for licencing in respect of heavy goods vehicles C1, C, D1, D, EC1, EC, ED1 or ED the directive permits for persons to be licenced to drive in these categories provided 10 years of seizure freedom have been achieved without the aid of anti-epileptic drugs. A permit may be granted in less time in the case of those with good prognostic indicators and in similarly in cases of juvenile epilepsy. Appropriate medical follow up must be completed and satisfactory result on neurological investigations. All persons are to be under licence review until they have been seizure free for at least 5 years.

In the case of applicants with epilepsy for licencing in respect of heavy goods vehicles C1, C, D1, D, EC1, EC, ED1 or ED the directive permits for persons to be licenced to drive in these categories provided 10 years of seizure freedom have been achieved without the aid of anti-epileptic drugs. A permit may be granted in less time in the case of those with good prognostic indicators and in similarly in cases of juvenile epilepsy. Appropriate medical follow up must be completed and satisfactory result on neurological investigations. All persons are to be under licence review until they have been seizure free for at least 5 years.

Persons who have had a provoked seizure due to a recognizable provoking factor that is unlikely to recur at the wheel may be declared eligible to drive on an

individual basis subject to neurological opinion with appropriate assessments having been completed after the acute episode.
First or single unprovoked seizures: the person may be declared fit to drive in these categories once 5 years seizure freedom has been achieved without the aid of anti-epileptic drugs. Drivers with good prognostic indicators may drive sooner.
Seizures due to drug or alcohol misuse, sleep deprivation or structural abnormality are not considered provoked seizures for licensing purposes. Reports of seizures due to side effects of prescribed medication do not automatically imply that such events will be considered as provoked.
Seizures which may be considered provoked include ecliptic seizures, reflex anoxic seizures, immediate seizure seconds after head injury, seizure in the first week post head injury not associated with damage on CT or MRI nor with post amnesia of more than 30 minutes, seizures at time of stroke/TIA or within 24 hours of same, seizures during inter-cranial surgery or the ensuing 24 hours.
Seizures associated with acute exacerbation of Multiple Sclerosis or Migraine need to be assessed on an individual basis by a Neurologist.

*Road safety Authority, 2010, website www.rsa.ie

APPENDIX 14: Epilepsy and its' hidden consequences

"A school cannot exist as a permanent form of education... It can only exist until the student discovers that they can learn more themselves from the real world... From that moment on the majority always look for the most promising place giving the highest wisdom outside of school, with the result of schooling always collapsing over 'life's education"

(Oosterhuis, 1999, p94).

"People with Epilepsy now that the day of the storm will come, but embrace the day as if it won't"

(Sillanpaa, 1992, p447).

"The word epileptic, should not be used to describe somebody who has epilepsy, as it defines a person by one trait or problem. A label is powerful and can create a limiting negative and stereotyping. It is better to refer to someone as 'a person with epilepsy' or to a group of people, 'people with epilepsy', Therefore, People with epilepsy are not Epileptic'"

(Anderson et.al, 2007, p134).

"Epilepsy is often called a "hidden disability" because the person may have no physical effects but behave very differently."

(Besag, 1994, p573).