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UCC
University College Cork, Ireland
Coláiste na hOllscoile Corcaigh

Students with epilepsy, their experiences in school and with State exams.

Sarah Cooke

CARL Research Project
in collaboration with
Epilepsy Ireland

CARL
COMMUNITY - ACADEMIC
RESEARCH LINKS
University College Cork, Ireland

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Date completed:	28/3/17

What is Community-Academic Research Links?

Community Academic Research Links (CARL) is a community engagement initiative provided by University College Cork to support the research needs of community and voluntary groups/ Civil Society Organisations (CSOs). These groups can be grassroots groups, single issue temporary groups, but also structured community organisations. Research for the CSO is carried out free of financial cost by student researchers.

CARL seeks to:

- provide civil society with knowledge and skills through research and education;
- provide their services on an affordable basis;
- promote and support public access to and influence on science and technology;
- create equitable and supportive partnerships with civil society organisations;
- enhance understanding among policymakers and education and research institutions of the research and education needs of civil society, and
- enhance the transferrable skills and knowledge of students, community representatives and researchers (www.livingknowledge.org).

What is a CSO?

We define CSOs as groups who are non-governmental, non-profit, not representing commercial interests, and/or pursuing a common purpose in the public interest. These groups include: trade unions, NGOs, professional associations, charities, grassroots organisations, organisations that involve citizens in local and municipal life, churches and religious committees, and so on.

Why is this report on the UCC website?

The research agreement between the CSO, student and CARL/University states that the results of the study must be made public through the publication of the final research report on the CARL (UCC) website. CARL is committed to open access, and the free and public dissemination of research results.

How do I reference this report?

Author (year) *Dissertation/Project Title*, [online], Community-Academic Research Links/University College Cork, Ireland, Available from: http://www.ucc.ie/en/scishop/completed/ [Accessed on: date].

How can I find out more about the Community-Academic Research Links and the Living Knowledge Network?

The UCC CARL website has further information on the background and operation of Community-Academic Research Links at University College Cork, Ireland. http://carl.ucc.ie. You can follow CARL on Twitter at @UCC_CARL. All of our research reports are accessible free online here: http://www.ucc.ie/en/scishop/rr/.

CARL is part of an international network of Science Shops called the Living Knowledge Network. You can read more about this vibrant community and its activities on this website: http://www.scienceshops.org and on Twitter @ScienceShops. CARL is also a contributor to Campus Engage, which is the Irish Universities Association engagement initiative to promote community-based research, community-based learning and volunteering amongst Higher Education students and staff.

Are you a member of a community project and have an idea for a research project?

We would love to hear from you! Read the background information here http://www.ucc.ie/en/scishop/ap/c&vo/ and contact us by email at carl@ucc.ie.

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Notwithstanding the contributions by the University and its staff, the University gives no warranty as to the accuracy of the project report or the suitability of any material contained in it for either general or specific purposes. It will be for the Client Group, or users, to ensure that any outcome from the project meets safety and other requirements. The Client Group agrees not to hold the University responsible in respect of any use of the project results. Notwithstanding this disclaimer, it is a matter of record that many student projects have been completed to a very high standard and to the satisfaction of the Client Group.

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1 INTRODUCTION

This study will carry out research into the lives of students with epilepsy in relation to their school, learning experiences and state exams. This study is relevant as epilepsy is a very common condition, 1 in 115 people have epilepsy which is over 37,000 people in Ireland (Epilepsy Ireland, 2017). Most people have their first seizure before the age of 20, so many children of schooling age are affected by the condition. Research conducted by Thompson (1987) indicated that children with epilepsy are also at a significant risk of developing learning difficulties, with problems occurring in between 5-50% of such children. School can be a struggle for students with epilepsy who are experiencing seizures and therefore resulting in disruptions in their school days. Even a single seizure in a day can cause memory loss and they can often forget what they just learned. Learning problems can sometimes emerge due to seizures or medication which may cause a child to fall behind in school. A student's memory, concentration and attention can be affected. Epilepsy can also cause students to miss days of school due to hospital visits or night time seizures.

This research project is being carried out in partnership with Epilepsy Ireland through Community-Academic Research Links (CARL). CARL is an initiative in UCC that develops a partnership between themselves, students and a community/voluntary group who collaboratively engage in research with the purpose of solving a pressing community problem. The students work with the community organisation to define the research questions and develop appropriate strategies to address those questions (Strand et al.2003, pp. 3, 8). Community based research values the knowledge and input from every group involved in

the research. One of the most important features of community based research is that it offers community/voluntary organisations and agencies a strong information base from which to plan and act upon (Strand et al, 2003).

Epilepsy Ireland (original called Brainwave) was established in 1966 by a group of individuals concerned to improve the quality of life of people with epilepsy in Ireland. Epilepsy Ireland's vision is to achieve a society where no person's life is limited by epilepsy. They are committed to working for, and to meeting the needs of everyone with epilepsy in Ireland and their families and carers. They also aim to raise awareness about epilepsy and improve public understanding to try to reduce prejudice and eliminate fear.

This report will begin by reviewing literature and policies related to epilepsy. Following a review of the literature, support and assistance for students with epilepsy will be explored. This research project used a qualitative approach to research, seven interviews were carried out with people who have epilepsy (18 years +) and attended school. Open-ended questions were used to get a full understanding and insight into the student's experiences. The methodology used throughout this research will be discussed in more depth in the methodology chapter. After carrying out the research interviews the results and findings will then be presented through thematic analysis. The final chapter will then discuss the findings and make a conclusion.

The research aim of this project is to explore how epilepsy affects students in school.
The research objectives include:

- Did they miss many days of school due to their epilepsy?
- Did they feel like they were treated differently because of their epilepsy?

- What supports (if any) were provided or offered to them in school?
- What supports (if any) were provided or offered to them for State Exams?
- Does stress contribute to seizures?
- What supports they think should be developed to help current and future students with epilepsy.

2 LITERATURE REVIEW

This chapter will focus on examining and identifying various pieces of literature relating to epilepsy, including books, journal articles, newspaper articles, websites, and scholarly articles. The findings will be presented as follows:

- Introducing and defining epilepsy.
- Classifications and types of seizures.
- Attitudes and stigma towards epilepsy.
- Prejudice in schools.
- Education; difficulties and challenges.
- Personal stories
- Conclusion

2.1 INTRODUCING AND DEFINING EPILEPSY

Epilepsy is defined in the Handbook of Epilepsy Treatment (Shorvon, 2005) as a disorder of brain characteristics by an ongoing liability to recurrent epileptic seizures. An epileptic seizure is defined as the transient clinical manifestation that results from an episode of neuronal activity. According to Smithson (Smithson and Walker, 2012), epilepsy is one of the oldest recorded medical conditions. The first known written reference to epilepsy was almost 3000 years ago in a Babylonian cuneiform, which described it as some form of possession by a demon or spirit. Almost 500 years after this the same concept was presented in Greek texts. The word Epilepsy was derived from a Greek word meaning '*to be seized, to be overwhelmed by surprise'*. The Ancient Greeks believed that only the Gods could take

over somebody's body in this way so that they may become unconscious or move uncontrollably and then afterwards come back around with no apparent ill effects or damage done.

The modern view of epilepsy originated in the work of the mid nineteenth century neuroscientists. Of whom John Hughlings Jackson was possibly the most significant. He defined epilepsy as '*occasional, sudden, excessive, rapid and local discharges of grey matter'* (Trimble and Reynolds, 1981). However, modern epileptologists have defined and redefined the various forms of epilepsy. Engel (1995) states that at present, the word 'epilepsy' is used to refer to '*a class of epileptic disorders, defined as chronic neurological conditions characterised by recurrent epileptic seizures*.' According to the World Health Organisation, an epileptic seizure is the result of transient dysfunction of part, or all of the brain due to excessive discharge of a hyper excitable population of neurons, causing sudden and transitory phenomena of motor, sensory, autonomic or psychic nature (Gastaut, 1973).

2.2 CLASSIFICATIONS

The terminology and classifications of epilepsy have evolved over many years of research. Recently there has been a realisation for the need of common, international terminology. This is important for those who are researching the area of epilepsy so they can communicate with one another and exchange various findings, ideas and results (Senior, 2003).

In 1964, an international committee was convened by the International League Against Epilepsy (ILAE) to create a comprehensive classification of epilepsy and types of seizures. Following on from this, a classification known as the International Classification of Epileptic Seizures was published (Gastuat, 1970).

Seizures were classified as:

1. Partial, or those beginning locally
2. Generalised, or those which are bilaterally symmetrical and without local upset. These may be convulsive or non-convulsive in nature.
3. Unilateral seizures
4. Unclassifiable seizures

This classification was then revised in 1981 (Commission on Classification and Terminology of the ILAE, 1981). The main reason this was revised was because it lacked some valuable well-known terms, e.g. generalised tonic-clonic seizure instead of grand mal. In 1985, this classification was supplemented by a classification of epilepsies and epileptic syndromes. In 1989, the Commission on Classification proposed a new International Classification of Epilepsies, Epileptic Syndromes and Related Seizure Disorders (Commission on Classification and Terminology of the ILAE, 1985, 1989).

2.3 Attitudes and Stigma towards Epilepsy

Among the many illnesses and medical conditions which exist, epilepsy has always been regarded with some awe and fear (Dinnage, 1986). Following the ancients beliefs and myths about epilepsy it is not surprising that it can still carry a stigma in today's society. Dell (1986), defines stigma as the relationship '*between the differentness of an individual and the devaluation society places on that particular differentness'*. Even though treatment and attitudes towards epilepsy have developed a lot, de Boer (1995, 2010) believes not all problems have been solved. Beliefs that epilepsy is caused by evil spirits, witchcraft, or weakness persist in some cultures and regions of the world (de Boer, 2010). Surveys indicate

that some people in the United States consider epilepsy a mental health condition or believe that it may be contagious (DiIorio et al., 2004; Sirven et al., 2005).

People with epilepsy are particularly susceptible to stigmatisation given the unpredictability and loss of bodily control that often accompanies seizures (Jacoby et al., 2005). Gordon and Sillanpaa (1997) stress how the attitudes of others towards a person with epilepsy can have a great effect on that person's life. This applies to people of every age but is particularly present in childhood. Epilepsy is still shrouded in misinformation and misbelief. For many people with epilepsy, coping with the stigma surrounding the disorder can in fact be more difficult than the epilepsy itself (Commission for the Control of Epilepsy and its consequences 1978). Stigma is linked to a broad range of psychosocial consequences, including a loss of self-esteem, social withdrawal and isolation, often influencing others within the social network (Link et al., 2001). Too often, the stigma attached to having epilepsy can mean that those with the condition are marginalised; prevented from participating fully in life, school and work. Epilepsy literature indicates a high prevalence of depression and anxiety in this population, arising from perceived stigma (Rafael, 2010). A major cause for a reduced quality of life of people with epilepsy is the prejudice that comes with the disease, mostly due to ignorance about its nature (ILAE, 2013).

There has been a number of international studies and surveys carried out on public awareness and attitudes towards people with epilepsy. One of the most controversial studies completed by Bagley (1972), found that a large proportion of the respondents opposed the employment of people with epilepsy. Baker et al. (1997) conducted a survey on the quality of life for people with epilepsy in fifteen countries in Europe. It reported that over half of all respondents (n=2,525) felt stigmatised by their epilepsy. The influential role of the news and

entertainment media should also be highlighted. As Coelho (2006) noted in an editorial in Epilepsy and Behaviour, "*The cloud grows darker each time the media … portrays epilepsy in a way that highlights myths, misconceptions and misunderstanding*" (p. 3). Chung et al. (1995) states that establishing the degree of awareness and understanding of epilepsy in a society is a necessary initial step in eliminating discrimination against people with epilepsy.

2.4 Prejudice in relation to School

Although prejudice and stigma exists at all ages, it can be particularly challenging for children at school. Many surveys have been carried out internationally to research the prejudice children experience in school. These surveys aimed to discover the attitudes of parents, students and teachers towards children with epilepsy in the class.

A. In a telephone survey conducted by Baumann et al. (1995), it was found that 24% (n=148) of Kentuckians predicted a deterioration in the classroom environment if a child with epilepsy was admitted. 41% (n=253) said that the quality of their child's life would be lowered by the time he or she reached the age of 21 years, if children with epilepsy were admitted to the class. They concluded from these statistics that in that particular area of the United States there is still a lot of prejudice towards people with epilepsy, and although it is important to improve people's knowledge of epilepsy, they are not convinced this will be enough to eliminate the prejudice.

B. A study was carried out on the socialisation patterns among 15 university students with epilepsy in Canada and Andermann (1992). This study reported that students were selective in the information they shared about their seizures to other students, staff and employers. Most admitted they preferred to only share this information with

their close friends. 53% of the subjects said that their epilepsy had not interfered with their studies in any way. They reported that if the epilepsy was diagnosed in elementary school or early high school, their teachers were made aware of this and were mostly understanding and accommodating to any of their specific needs. However, their classmates were not as understanding and this caused problems for several of the students. By the time these students reached university they concluded that most of these conflicts were resolved and they had developed a close circle of friends who knew about and understood their epilepsy. However, all of the subjects were aware of prejudice in society and believe it was necessary for further education of the public about epilepsy to reduce this prejudice and stigma to improve the quality of their time spent in education.

C. Holdsworth and Whitmore (1974), in a survey of the information and attitudes held by head teachers and class teachers in 60 mainstream schools that had children with epilepsy, found that in general they were sympathetic towards the children and were anxious to treat them as normally as possible. When asked if they were uneasy about, disliked or accepted having a child in their class with epilepsy only 3.3% (n=2) said they would prefer not to admit a child subject to major fits. However this question elicited a certain amount of anxiety among the other 57 head teachers, all of whom at some point had a child with epilepsy in their school. Some said they would have been more comfortable accepting these children if they had known what to do in the event of a major seizure. Others said they were less concerned with the possibility of a major seizure and more worried about their general management, mainly because of what the parents had told them. Holdsworth and Whitmore (1974) felt that the tolerance of some head teachers had misled them into accepting (perhaps even

expecting) a lower level of work from a child with epilepsy. Others who have studied children with epilepsy have similar opinions (Ounsted et al., 1966; Green and Hartlage, 1970).

D. Bannon et al. (1992) conducted a survey of perceptions of childhood epilepsy among 142 mainstream teachers in North Straffordshire. Although this survey revealed more positive findings regarding teachers' perceptions than those found by Holdsworth and Whitmore (1974), only 5% (n=7) of the teachers reported that they felt 'very confident' when dealing with children who had epilepsy, 31% (n=44) felt 'quite confident' and 64% (n=90) replied that they 'did not feel confident'. Only 4% (n=5) felt that they knew enough about childhood epilepsy, 87% (n=120) considered their knowledge inadequate, and remaining 9 %(n=12) were not sure. Bannon et al. (1992) believe that if a good quality of care for children with epilepsy is to be achieved then teachers must feel more confident with the condition. They believe the school health services had a role in ensuring that all teachers have sufficient knowledge and adequate support.

E. A study was carried out in the city of Campinas in Brazil (2007) to compare the stigma perception of epilepsy, to two other chronic conditions including AIDs and diabetes. People were interviewed in two different settings: (i) On the streets (145 randomly selected) and (ii) During an epilepsy meeting (86 people). They were asked to rate the score for the prejudice that the general population had towards epilepsy, AIDS and diabetes. The score ranges from 0 (no prejudice) and 10 (max prejudice). The results for the lay people were: AIDS=9, epilepsy=7 and diabetes = 2. The results for the people with epilepsy were: AIDS=9, epilepsy=7 and diabetes=2.5. It has been

argued that an individual's self-image is threatened only when the person accepts the social devaluations of their condition (McLin and Boer, 1995) (Morrell, 2002). However these results show the same pattern of perception by lay people and people with epilepsy.

F. A study was carried out last year (April 18, 2016) called *Experiences of university students disclosing epilepsy to peers: "It's a shared thing now".* The aim of this study was to highlight the process of peer disclosure by university students with epilepsy. The key findings of this study showed that: Epilepsy interfered with participants' authoring of their own lives; the main obstacle to disclosure was social stigma; and disclosure helped participants restore personal control and attain meaningful participation (Sheridan, Salmon and O'Connell, 2016).

Epilepsy is the most common serious neurological condition (WHO, 2015). Every year in Europe 240,000 babies are born who will later develop epilepsy (de Boer, 1995). In Ireland up to 36,844 people over the age of 5 have epilepsy (Epilepsy Ireland, 2013) and up to 600,000 in the UK (Joint Epilepsy Council of the UK & Ireland, 2011). It is for these children we must try to improve the education system for people with epilepsy and to cut down on the stigma and prejudice that exists in today's society. Gordon and Sillanpaa (1997) stress that society's attitudes must be changed and to be effective this change must begin in schools.

2.5 EDUCATION

Hoare (1984b) reports that school often becomes a challenging environment for children with epilepsy. Parents often worry that the epilepsy may be affecting the child's work and behaviour in class. A big cause of concern is for those parents who want to keep their child's

epilepsy a secret. This can cause potential danger for the child's health and also for the staff as they are not prepared for seizures which may occur (Ross and Tookey, 1988). As previously outlined, Holdsworth and Whitmore (1974) and Bannon et al. (1992) identified the lack of knowledge among school staff. From the research evidence, it emerged that teachers have an important role to play in ensuring that the children with epilepsy are comfortable at school and capable of reaching their full potential. Schools can reduce parents' anxieties and encourage independence and self-esteem if they have adequate knowledge about epilepsy. The difficulties that may arise in schools can be reduced by improving school awareness, developing a strategy for dealing with seizures, and providing resources needed. It is necessary for the teachers to have a greater understanding of epilepsy so that the child can have a normal school experience and feel included. For example, avoidance of computers on the basis of epilepsy is unnecessary as epilepsy is not proven to be photosensitive (Wallace, 1994).

Overall, children with epilepsy are at greater risk of learning and behaviour difficulties than children without epilepsy. These difficulties also affect children without identified special educational needs. A recent study found that these difficulties often go unrecognised and unsupported. It is important to think about the whole child, and consider all aspects of their life that might be affected by living with epilepsy. This is because learning, behaviour and wellbeing are all related to each other (Epilepsy.org.uk, 2017). School may cause significant difficulties for a child who has learning problems along with their epilepsy. Learning problems can emerge from seizures or medication and tasks that were previously routine may become increasingly difficult and students may feel themselves falling behind their classmates. Some specific learning problems that children with epilepsy can experience are: (Aboutkidshealth.ca, 2016)

- Academic problems; difficulties with reading, writing and maths.
- Language problems; difficulties with comprehension, speech and communicating with others.
- Attention and concentration problems; children with epilepsy might only be able to concentrate for short periods of time.
- Processing problems; it may take a student longer to process new information or take longer for them to complete tasks.
- Memory; they may struggle to remember topics they have learned.

These learning problems can often continue throughout their schooling, however they can also often experience disruption in their education due to their seizures, sleep patterns or medication. These disruptions which affect their attendance and ability to learn and concentrate can change from day to day. Frequent 'invisible' seizure activity in the brain during school can result in slow processing and loss of memory of information just learned. Night time seizures can increase fatigue during the school day. Leaving the child with less energy to concentrate and learn in class (Aboutkidshealth.ca, 2016).

A survey was conducted on parents' opinions on and experiences of provision for children with epilepsy in the Republic of Ireland. When asked about the children's participation in school related activities such as swimming, PE, school tours etc. 23% (n=15) had stopped participating. According to Thompson and Oxley (1993) restrictions can sometimes adversely influence the development of children with epilepsy and result in underachievement in school and delay in personal development. Holdsworth and Whitemore (1974) reported that head teachers had imposed restrictions on 31% (n=26) of the children with epilepsy attending mainstream schools.

In the same survey, parents were asked about educational difficulties their child may be experiencing. 48% (n=31) felt their child was progressing at a slower rate than other children their age. 51% (n=33) parents reported that their child was experiencing educational difficulties. The highest area of educational difficulties was concentration. In relation to disruptions in their education, 37% of parents reported that their child missed out on a lot of school work. This was due to some of the following reasons; attention and concentration difficulties when in school, general absences from school, tonic-clonic seizures, absence seizures while in school, hospitalisation, and tiredness. Two parents commented that their children were often late for school because of early morning seizures. In relation to exams, when asked if they were aware that special exam conditions are made available by the Department of Education and Science for children with epilepsy, only 23% (n=15) reported that they were, only 8% (n=5) of the children in the sample had specific State Examination conditions made available to them when sitting public exams. However, in 54% of the subjects such exemptions did not yet apply as the children were too young. When asked if they were satisfied with the range of special examination conditions available for children with epilepsy, 75% (n=49) of parents reported they were unaware of them. 17% (n=11) said they were happy, 8% (n=5) expressed dissatisfaction. One parent commented that she thinks State exams put too much pressure on a child with epilepsy and there should be monthly or continuous assessment. Another said her son did the Leaving Certificate twice, and they were never made aware of any special exam conditions.

Dr Veronica Lambert and Professor Pamela Gallagher from UCD conducted a study (2015) entitled "*Talking about Epilepsy*" which aims to find out why there is such a variety in family communications about epilepsy and the challenges for parents and children when it comes to talking about their epilepsy and its associated stigma. 40 interviews were conducted with

parents and 33 children (ages 6-16) living with Epilepsy in Ireland. Some reasons why parents did not tell others about their child's epilepsy included: they wanted as much as a normal life as possible for their child, they saw epilepsy as a largely hidden condition, they anticipated a negative reaction from others or had already experienced one or they feared public perceptions of epilepsy. Some parents were only coming to terms with diagnosis themselves and others were just private people. The things that stopped the children from telling others were: the fear of having a negative reaction similar to their parents, afraid of feeling different, a difficulty in explaining it to others, the child's own negative perception of epilepsy and also their parent's tendency for privacy. Some interesting themes also emerged in relation to education and epilepsy. There was some examples of positive experiences where teachers learned more about epilepsy in order to inform other students about epilepsy and were also accommodating to the child's needs. However there was also some more negative experiences, including a lack of proactivity to educate self and others about the child's epilepsy and placing unnecessary restrictions on the child. Findings revealed that how schools respond to an epilepsy disclosure can affect how parents and children communicate about their epilepsy in the future (O'Toole et al, 2016).

2.6 Personal Stories

Epilepsy Ireland aims to promote and raise awareness about Epilepsy, they share many personal stories on their website page which is a great way for other people to truly understand and gain an insight into the lives of people with epilepsy.

Maria Carty-Mole shared her story on the Epilepsy Ireland website in relation to her epilepsy and education. She outlined that epilepsy can have an effect on a young person's ability to get the most out of education. For some people it is not a problem but for others it can be with

frequent absence from school due to stress, hospital, bullying or low self-esteem; a loss of long or short term memory; side effects from medication e.g. Headaches; these are all extra challenges that students with epilepsy may have to face. Maria stressed that it is essential to look for support from the educational institution in which the student is studying. It was through the school that she was able to obtain a private room for her Leaving Certificate exams, which meant that if she was to have a seizure during an exam she would be given extra time to sleep and recover. Maria highlights that this was a huge relief for her as until then she was sure that if she had a seizure during an exam she would fail.

A young student named Sean Fenton who will be doing his Leaving Certificate this summer also shares his story of how epilepsy affects his education (McGuire, 2016). However his story is not as positive as Maria's. He said "*no real allowances are made for students who have seizures during a Leaving Certificate exam, even though it can seriously damage their prospects of reaching third level education".* For his Junior Certificate exams he was given extra time and his own room, but he experienced seizures during some of his exams. This left him unable to answer the questions. As the exams progressed the stress got worse which brought on more seizures. Unfortunately, he didn't get through all the papers. He outlines that what people with epilepsy or other neurological conditions need are spaced out exams or the possibility of splitting them across two years. Sean is now worried for his Leaving Certificate and explained that if he has a seizure then that exam is over for him, yes he can repeat them the following year but there is no guarantee that it won't happen again. The Commission says it has considered allowing students to sit an alternative exam on a different day but unfortunately the exam timescale and other difficulties make this impossible. It seems to be almost beyond their control, any change would have to be brought about by the government and supported by the Unions.

In the same article, another student named Katie tells her story. Katie will also be sitting her Leaving Certificate this year. However, Katie is unable to attend school as she has about 10 seizures a night, which wake her up and if she is really tired then she can have more serious seizures and end up in hospital. She gets about 10 hours of home tutoring a week but that's nothing compared to what other students have. The rest she is doing by herself. She relayed, the structure of the Leaving Certificate makes it impossible for her. Her brain is unable to function for two hours straight, never mind when she has 2 exams in one day, and it is also extremely difficult for her to write for that long. Katie is very worried for the Leaving Certificate and is hoping she will only have about three seizures during the exams, however she is unsure how she will get through a full week compact with exams, if she had a lot of seizures the night before an exam then she will find it extremely difficult to perform in an exam the next day.

Personal stories impact on epilepsy awareness as people can gain a greater understanding into the lives of people with epilepsy. Out of the 119,000 students who sat the Leaving Certificate last year, about 560 have epilepsy. Epilepsy Ireland estimates that at least 100 a year encounter some of the difficulties outlined above. However, this figure may be higher. Dr. Joyce Senior, director of the master's in education in UCD says students who have seizures cannot properly sit the exams and are essentially excluded from the CAO. The seizures can often be triggered by stress and tiredness which are comparable with the Leaving Certificate in general. The State Examination Commission's only concession-sitting an alternative paper under supervision, is not an option if the student has had a seizure and is exhausted or has another exam that day. Dr. Senior says "*For some, seizures make the Leaving Certificate*

process insurmountable, which limits their college and life choices. This is questionable in terms of equity and rights" (The Irish Times, 2017)

2.7 CONCLUSION

The literature reviewed in this chapter has identified that although there has been a lot of research and study carried out to improve the lives of those with epilepsy there is still a long way to go. The attitudes of society towards people with epilepsy must be improved. This can be brought about through education. This education should begin with target groups such as parents, doctors, teachers and employers. Many students are struggling in school due to the prejudice they are experiencing from other students. It is important to educate these students to try and eliminate the stigma surrounding epilepsy. In relation to education, it has been shown that a large proportion of children are experiencing educational difficulties. Possible effects on learning and behaviour are among the major concerns expressed in relation to children with epilepsy. Besag (1995) believes that learning difficulties may not only affect behaviour but can significantly influence the child's future. It is therefore necessary to improve the quality of information provided in Ireland about epilepsy. Teachers require better education about epilepsy, both before qualification and during in-service training. Throughout the formal education system, there should be promotion of positive attitudes towards children with epilepsy (Hauser and Pavone, 2003).

3 POLICY REVIEW

This chapter will focus on examining national and international policies relating to epilepsy. It will pay particular attention to dealing with epilepsy during school and exams. Unfortunately there is a lack of policies in Ireland explicitly related to epilepsy. Thus due to this the review will focus on educational legislation from England and Wales which offer as a guide. The English system works as a good substitute because the structure of the Irish and English systems are similar and have similar origins. Also, the educational provisions for special needs in Northern Ireland is very similar to that of England. This chapter will begin by discussing epilepsy institutions in England in the past and today. It will then outline the shift towards integration of these institutions and mainstream schooling. Following this it will take a look at the provisions in Ireland and Ireland's view on the integration module. It will then examine what accommodations are made for Irish students with epilepsy.

3.1 EPILEPSY AND INSTITUTIONS

In 1815, Esquirol, a 19th Century Physician, aimed to establish a special institution for people with epilepsy. His reason for this was, because he believed that if a healthy person witnessed a seizure, they too could become epileptic (Grant, 1981). There then became a demand for special institutions for people with epilepsy and these demands were fulfilled from 1860. Until 1981, there was 6 residential schools in England specialising in the treatment of epilepsy. However, the 1981 Education Act (enacted 1983), aimed at integrating these special schools into mainstream schools. This is in accordance with mainstream politics and is based on economic demands for more efficient methods of education (Aldenkamp et al., 1989). However, De Jong et al., (1997) argues that the current attempts to shift towards

mainstream education and adopt the Anglo-Saxon model of integration is inspired by economic rather than educational needs. This is a deeply worrying factor for all students with special needs, because their health and wellbeing is now secondary to saving money in the economy. The important decision making bodies in our country are making decisions based on what is most economical and as a result our students may suffer. Today, there are still 3 residential schools in England specialising in epilepsy. Children who attend these schools have severe epilepsy and/or educational difficulties. Besag (1988) states that most children with epilepsy are capable of attending mainstream schooling, however these institutions are important for the minority who need additional help and support.

3.2 INTEGRATION

The concern for children with epilepsy and their education is a relatively new innovation, until the end of the 19th Century most children with epilepsy received no education at all (Kurtz, 1983). In the early days of formal education there was very little help given to children with special needs and they therefore often struggled in school to keep up with the set curriculum (Rogan, 1980). It was not until the passing of the Education Act in 1918 that compulsory provision of education for children with epilepsy became a reality (DES, 1978).

The 1981 Education Act further developed the concept of integrated education and adopts a human rights based approach. Within the context of this act children were no longer categorised by their particular disability but rather as having Special Educational Needs. In this way the act attempted to take into account the whole child as an individual, including their strengths and weaknesses, rather than just concentrating on their disabilities. This was a great step for children with epilepsy who were no longer being defined by the type of seizures they had but could now be seen as much more than that.

The 1993 Education Act also introduced a Code of Practice to assess pupils with special educational needs. This was part of identifying those strengths and weakness, and following that, developing a plan of action to ensure the students could reach their full potential in school. Under Section 166, a Health authority must provide help to a Local Educational authority for a student who has special educational needs. This help may include providing advice or training to the school staff in relation to procedures to follow when dealing with a student's medical needs. It also recommended that the health and educational authorities and the school should work together in close contact with parents to ensure children with special needs are fully supported in school.

3.3 IRELAND AND INTEGRATION

Epilepsy Ireland (previously Brainwave - The Irish Epilepsy Association) agrees that integration is the solution and that it is not necessary to have separate education facilities for children with epilepsy. They believe that a child with epilepsy would develop best in the company of peers who grow to understand their condition and in turn help to improve their self-esteem, development and performance in class (Brainwave, 1991). However, although they encourage the education of children with epilepsy in mainstream schools they also recognise the need for special schooling for those children whose epilepsy is very severe or cannot be controlled by medication. However, after reviewing the provisions provided for students with severe epilepsy, it was found that these children are not supported within the Irish educational system. Ireland is the only country in the EU that has no special facilities provided for children with severe epilepsy (Brainwave, the Irish Epilepsy Association, 1991). The Irish Epilepsy Association is also aware that a number of children are being sent to

residential schools in England due to the lack of facilities available here in Ireland, however, exact figures were not available.

In the 1937 Constitution, it is the right of children to '*receive an education appropriate to their abilities, aptitudes and potential*'. Almost 60 years after this, the recognition of their right was reiterated in the White Paper on Education (1995). In order for this right to be achieved there must be extra provisions for those children with additional needs. However, it is evident that students with epilepsy needs are not being fulfilled. O'Toole (1998) believes that they best way to test a democracy is to view how it treats its minorities. He also believes that if we were to apply this test to the Irish education system at present, it would appear very negative. This would certainly appear to be true in the provisions for children with epilepsy. Educating a child with epilepsy in a special school for children with mental, physical or emotional disabilities, does not in any way benefit this child's education or development.

3.4 DEVELOPMENTS IN IRELAND

The National Clinical Programme for Epilepsy has a vision for the delivery of epilepsy care in Ireland. The vision is: "*To provide the best patient centred care for all people with epilepsy in the right place, at the right time, sharing the best available information*". This programme has made significant advances in the care of people with epilepsy and has reduced admissions of patients with epilepsy to hospitals and length of stay. However, although this programme has been effective in helping to improve the quality of care provided to people with epilepsy in hospitals, it has no effect on epilepsy at school. It is the nurses and physicians that are aware of this program not our teachers.

"Every child with a disability has the right to reach their full potential" (NDS, 2011). The policy framework for children with disabilities and special education needs is set out in the Education for Persons with Special Education Needs Act 2004. This states that every child with a disability should be educated in an inclusive environment where possible and appropriate. The National Disability Authority focuses in particular on the interface between education and other policy areas, and is informed by research and consultation. They also work closely with the National Council for Special Education which had a statutory role to undertake research and provide policy advice on education matters.

A study was carried out by the CHESS group called 'The Identification of Education Problems in Childhood Epilepsy'. This study arose from a senior politician saying *"I know that people with epilepsy are not counted in schools and I know that they have a wide range of cognitive and behavioural problems but you have to do something that brings this to everyone's attention"*. The committee responded to this by organising four international annual meetings that highlight these problems, a new course for professional and The CHESS Study. The purpose of this study was to highlight what cognitive and behaviour difficulties were present in children ages 4-16 with epilepsy. The study highlighted many significant issues including; very high levels of problems with academic progress; 42% were underachieving in processing speed; 60% met the diagnostic criteria for a behavioural disorder or DCD; 95% of the children had difficulty in at least one of the assessed areas and most of the children had several problems. This study was successful in identifying the problems that exist, however of those with significant behavioural problems, only one third had been previously diagnosed. This study highlights the need for a clinically orientated educational psychologist to perform assessments on all children with epilepsy. The following step in the process will be a combined approach from parents, children, teachers and other

professionals, to aim to fulfil the rights of children with epilepsy by early, comprehensive assessments.

This study suggests that academic and behavioural difficulties in childhood epilepsy are overlooked due to the need to manage seizures. Parents and teachers reported a high level of concern towards academic progress and behaviour. Parents also said that epilepsy can cause difficulty with attendance at school. Over half of the children with epilepsy in this study had an IQ below 85, which is likely to have a significant impact on progress across the school curriculum.

Any guidelines that exist for the management of childhood epilepsy focus primarily on seizure management. However, they fail to consider other academic or behavioural difficulties. Consequently, students are not receiving any treatment or help for these difficulties. This likely contributes to further difficulties with academic progress and has a significant negative impact on the quality of life of these children and families.

3.5 In School

Epilepsy Ireland provides information on what help is available in schools. If the child has also been diagnosed with another disability or learning disability they may be entitled to resource teaching hours. Unfortunately, many children with epilepsy don't fit the criteria and are not eligible for resource teaching. The National Council for Special Education (NCSE) has responsibility for providing these resource supports and SNAs for care needs in schools throughout the local SENOs. The NCSE was set up in 2003 to improve the delivery of education services to people with special educational needs, with particular emphasis on children. The service is delivered through Special Educational Needs Organisers (SENOs) who interact with parents and schools, who liaise with the HSE in providing resources for

children and their special educational needs. If a child does not get access to a resource teacher, but is struggling in class, they may be referred to Learning Support for a time, this decision is made by the school.

In relation to state exams, students with epilepsy can apply for RACE or Reasonable Accommodations in Certificate Examinations from the State Examinations Commission. This usually consists of a separate room and supervisor during the exam, which can take away some worries about having a seizure in public. They may have a rest break which is added on to the end of the exam. If a seizure happens during the exam the student can complete the exam up until midnight that day provided they remain under supervision. In cases of sleep or early morning seizures medical evidence may be taken into account if the student misses the morning exam or part of it.

Current legislation requires that reasonable accommodations are made to prevent issues of discrimination regarding access issues. Examples of reasonable accommodations may include the provision of an LCD or TFT monitor for a student with photosensitive epilepsy. Other accommodations may involve providing a quiet place for the student to recover after a seizure rather than sending them home.

A valuable resource pack for teachers and parents called "Managing Chronic Health Conditions at School" is easily accessible online. This document covers a range of conditions and has a section focused on epilepsy set out by Epilepsy Ireland. It begins by outlining a sample epilepsy emergency plan for schools. This involves a checklist of do's and dont's depending upon the type of seizure. It also explains when it is necessary to call an ambulance and provides the emergency contact numbers. Following this, it provides detailed lists of

responsibilities for the school's Board of Management, teachers and parents. This document is of great use for school staff as it provides a lot of valuable information regarding epilepsy and in particular students with epilepsy. It identifies the effects a student's epilepsy might have on them at school.

Seizures are just one aspect of epilepsy that can affect their education. A student may experience many seizures during one day of school and this can make concentration and learning very difficult. Epilepsy can also have many other effects which are not always easily identified such as night-time seizures which can leave the student exhausted and unable to concentrate in school. As with any students, those with epilepsy may experience psychological and social factors which can affect their behaviour and learning. These may range from issues of stigma and exclusion to issues of confidence, fear and anxiety, low self-esteem, and lack of memory or concentration. Therefore sensitive input from school staff is important to prevent this. Other students should be aware of epilepsy and have some understanding of the condition to try and break down any stigma. This awareness could be raised through SPHE or science class, or a guest speaker from Epilepsy Ireland could come to speak to the class and inform them about the condition. This learning experience does not mean students with epilepsy have to identify themselves as having the condition unless they want to. But hopefully these classes would create a climate of understanding among all students and staff (Brainwave, the Irish Epilepsy Association).

3.6 CONCLUSION

There was six major educational policy documents published during the 1990s in Ireland. However, special educational needs for children with epilepsy were not mentioned in any of these documents. Furthermore, children with epilepsy do not even come under the definition

of children with special needs as cited in any of these documents. Therefore, it could be concluded that children with epilepsy have no entitlement to any special assistance in educational provision nor does any such entitlements even exist with the Irish Law (Senior, 2003). This therefore demonstrates the relevance of this study, to hear the voices of students with epilepsy and to understand their experience of education. Considering that those with epilepsy are not catered for in the Irish Educational System and given the number of students with epilepsy, it is especially timely that such views are captured.

4 METHODOLOGY

Aim:

The aim of this research is to develop a greater understanding into the lives of students with epilepsy at school. The researcher aims to highlight a student's experience of going to school with epilepsy; including their day to day lives, stigma, school and exam supports and worries. The research objectives include:

- Did they miss many days of school due to their epilepsy?
- Did they feel like they were treated differently because of their epilepsy?
- What supports (if any) were provided or offered to them in school?
- What supports (if any) were provided or offered to them for State Exams?
- Does stress contribute to seizures?
- What supports they think should be developed to help current and future students with epilepsy.

4.1 QUALITATIVE RESEARCH:

Qualitative research enables nuanced understanding of varied life experiences to be represented (Kincheloe and McLauren, 2002) and thus is suited to achieve the research aims of this project. Qualitative research is a research strategy that usually emphasises words rather than numbers in the collections and analysis of data. Qualitative methods are appropriate for this study as it provides an in-depth examination of cases because they aid the identification of key features. Most qualitative methods enhance data (Ragin and Amoroso, 2015). Qualitative research is relevant to this study as it involves the use of interviews to gain a deeper understanding into the lives of students with epilepsy. As a research method, qualitative research is broadly inductivist, constructionist and interpretivist, but does not always have to be all three (Bryman, 2012).

- Qualitative research is inductive in that researchers build their own patterns, categories and themes from the bottom up by organising the data into increasingly more abstract units of information. This inductive process involves working back and forth between the theme and data until a comprehensive set of themes have been developed. It often involves communicating with the participants and allowing them the chance to shape the themes also (Bryman 2012).
- Qualitative research also holds an ontological position described as constructionist, which implies that social properties are incomes of the interactions between individuals, rather than phenomena 'out there' and separate from those involved in its construction (Bryman, 2012).
- Qualitative research involves an epistemological position described as interpretivist. This means that unlike quantitative research which adopts a neutral scientific approach, qualitative researchers put emphasis on understanding the social world through examination of the interpretations of that world by its participants (Bryman, 2012)

4.2 Qualitative Research Characteristics:

Qualitative research often involves a smaller number of participants. This may be because the methods used, such as in depth interviews, are much more time consuming than quantitative methods such as surveys. However this does not make the study any less scientific (Bryman, 2012). Qualitative research aims to carry out its study in a calm relaxed environment so that the information is gathered by actually talking to people directly and observing their body language and reactions (Cresswell, 2015). The entire project is focused on the participants experiences and learning from them. It is important to learn about epilepsy from the participants who actually have it rather than the researcher learning solely from literature.

Qualitative research must also allow for flexibility. This means that the initial research plan cannot be tightly prescribed. The planned process may easily change once the researcher had entered the field and begins to collect data.

4.3 LIMITATIONS OF QUALITATIVE RESEARCH:

- Bryman and Burgess (1999) observe that sometimes qualitative research is discussed in terms of the way in which it differs from quantitative research, this can sometimes be a problem as qualitative research is then being addressed in terms of what quantitative research is not.
- Qualitative research can sometimes be criticised as being too impressionable and subjective. Some people believe that qualitative research can rely too much on the researcher's views. They feel it is the researcher's own task to decide what information is relevant or important from the interview, and therefore may result in some bias.
- Qualitative research is a form of interpretive inquiry in which researchers make an interpretation of what they see, hear and understand. Their interpretations cannot be separate from their own backgrounds, history contexts and prior understandings. After a research report is issued, the readers make another interpretation of data. In the end, the readers, participants and researchers all make interpretations so it is clear how multiple views can emerge.
- It may be difficult to replicate a qualitative study. Basically, because it is not fully structured and often relies upon the interviewees answers. Each participant can answer each question completely differently which may lead to additional varying questions.
- Transcribing, interpreting and analysing the data can be very time consuming.

4.4 PROCESS OF CARRYING OUT RESEARCH:

To begin the interview process, the researcher must gather a sample. Sampling is a method for "*collecting information and drawing inferences about a larger population or universe, from the analysis of only part thereof, the sample*" (Scott and Marshall, 2005:574). This research involves non-probability sampling called purposive sampling as it involves people who meet particular characteristics e.g. have epilepsy and attended school. This research could not use random sampling as it would make no sense to interview someone about epilepsy if they do not have it. Once the sample has been developed the interview process begins. This research will involve semi-structured interviews, this is when the researcher prepares a list of questions on specific topics to be covered. The researcher draws their questions from literature and policy reviews and their research aims and objectives. The key feature of this form of interview is flexibility. The interviewer can change questions or add additional questions in response to the participant's answers. Questions should be clear and unambiguous. The researcher should never ask more than one question at a time. It is also beneficial to include open-ended question to get a more extensive and deeper answer and understanding.

4.5 BENEFITS OF INTERVIEWS

Interviews are very beneficial as it gives people the opportunity to respond with spontaneity rather than selecting their answers from pre-determined responses. Interviews aim to create a relaxed atmosphere between the researcher and the participant so that the participant is encouraged to express themselves fully. This may mean adopting a less formal and less rigid atmosphere than that used in quantitative research. For the purpose of this study interviews are far more beneficial than surveys. By carrying out a survey or other forms of quantitative research we are limiting the study to the researcher's view or understanding of the situation

and therefore it is unlikely to learn anything new about the experiences of the participants. Interview questions can be much more open-ended, less narrow and more exploratory. The researchers are free to expand their questions in response to the answers the participants give. In this way each interview will be unique and show different answers.

4.6 Ethical issues

Before beginning the interviews, the participant must read and sign a consent form. They must be aware of what the research involves and what their role in the research is. They must know it is their own choice if they would like to participate or not and they have the right to withdraw at any time during the research. The participants and researcher can then keep a copy of the signed consent form. When writing the results each participant must be kept anonymous. For this reason each interview will be given a case letter and no identifying information will be used. The research must respect the participant and not pressure them to answer any question they may feel uncomfortable about. The interviewer must respect their privacy and emotional wellbeing. Finally, the data must be stored safely and privately.

4.7 Data collection and Analysis

Data analysis is the process of reducing large amount of data to a smaller story or interpretation. This researcher used thematic analysis which involved coding interview transcripts, clustering codes into key concepts or categories and developing, then testing themes that arose from mapping out connections and contrast among these concepts to clarify the phenomena under investigation (Braun and Clarke, 2006).

The approach to data collection and analysis is methodical but allows for greater flexibility than in quantitative research. Data is collected from observation and interaction with participants. It is not converted into numerical form and is not analysed through statistics. The researcher will transcribe all the interviews and then present the findings in the report. The findings will then be discussed and a conclusion will be made from this.

5 FINDINGS AND ANALYSIS

Introduction

The researcher conducted seven interviews with people ranging from ages 19-47 which include both male and female participants. These interviews were conducted face-to-face, over the phone and via email. This chapter will outline and present the findings from these interviews. Thematic analysis yielded six main themes:

5.1 School attendance

5.2 School performance

5.3 School supports

5.4 State Exam supports

5.5 Stigma and prejudice

5.6 Stress

In order to keep the participants in this study anonymous, the participants will be categorised by letters.

The participants are as follows:

Letter	Gender	Age	Type of epilepsy
A	male	47	mal-type
B	female	19	A-tonic & Tonic-clonic
C	female	25	mal-chronic
D	female	21	Tonic-chronic & absences
E	female	27	all types
F	female	19	petit-mal
G	female	19	Myoclonic

5.1 SCHOOL ATTENDANCE.

Unfortunately, epilepsy has shown to have an effect on students' attendance in school for 80% of participants.

"I missed over half of 2nd year as I was having seizures constantly maybe 3/4 in a week and I spend a lot of time outside school" (E)

Participant B had her first seizure when she was 16 but was not diagnosed with epilepsy until she was 17. She was having about 6/7 seizures a day for about 11 months before they knew what it was from. She was physically unable to attend school during this time and spent a lot of time in and out of hospital. She had to repeat 5th year as she missed so many days of school. However once they discovered it was epilepsy she was put on medication, which helped a lot. She was still having seizures but not as many. When she returned to school the school made a strong suggestion to her parents to stop attending school until she *"got sorted"*. *"I suppose they thought it was dramatic for other students to witness - which is true, but I don't think they really took my perspective into account"*. She then moved school and thankfully the new school was really nice and very understanding. *"I'd have a seizure in class and the class would just carry on because it happened so often".* A lot of the time she wouldn't do homework because she was just really tired but she explained how she was '*lucky'* in that the teachers didn't mind or would never question her as to why she didn't have homework done.

Participant C explained that up until her diagnosis she had perfect attendance but following first year she started missing many days of school and was often late. "*I'm not sure exactly how many days I missed during 2nd/3rd year but I know in 4th year I missed over half the*

year". This was due to several factors but she explained most of the time it was due to side effects from medications. She would often wake up with jerks in her hand which would put her off for the day, and if they got worse throughout the day this would lead to a seizure so a lot of the time she would stay at home. She also experienced a lot of Migraines which played a big part in her attendance and made it impossible to go to school. She also said that maybe age was a factor, because she still has most of the same side effects but will still attend work. "I *suppose in school with the social situation as well, I often didn't want to go in.*"

Participant F also missed a huge amount of school. She said she missed 60% of 5th year and 50% of 6th year. This made it more difficult for her to keep up with her classmates. She also added that when she was in school she was always "*completely overtired*" as a result of her medication and was often falling asleep and feeling unwell.

Participant G said she missed a few days of school, she missed 2 weeks straight when she was in hospital being diagnosed. Also whenever she had a grand-mal seizure she would be "*bedridden for 2 days".*

However Participant A and D didn't miss much school. "*I would only be absent the day I had the seizure and would always be in the next day"*. (D) Participant A missed very little days in general only for routine check-ups which only happened maybe once a year.

5.2 SCHOOL PERFORMANCE

All participants said they did not experience any additional learning difficulties because of their epilepsy. In general they found they were still able to work hard in school and achieve good results. However, for those who missed a lot of school, they said at times it was hard to keep on top of everything.

"*When I was in school I struggled with concentration*". (D) She explained that often in class she would zone out and found it very difficult to listen and concentrate for any length of time. She feels that this had an effect on her exam results and general performance in school.

Participant A said "*If I'm honest, I might have used it as an excuse… I wasn't very sports minded so I used it as an excuse to get out of PE*" He didn't feel that his epilepsy had an effect on his academics at school and continued to work hard.

Participant F emphasises the fact that although epilepsy does hold her back in many ways, she is also well able in many ways. She stressed the fact she has never had any repeats and never failed an exam. "*When I'm able to study, I'm able to learn like any other person"*.

Participant G expressed that her experience in school could often be very stressful. As stress would build up coming up to exams, she would start to have more and more absences (a few a day), which would cause her to lose concentration several times throughout a class, meaning that she would sometimes miss vital points in class and fall behind. She also said that her seizures were partially due to lack of sleep, "I *could not stay up late to study, as many of my friends could"*.

5.3 SCHOOL SUPPORTS.

What supports were offered to students depended a lot on what school they attended. Most students said they were offered no supports.

Participant A received no additional help but he explained he went to school during the 80s so they didn't exactly expect anything "*The mother asked the headmaster to look out for me and that was it*".

Participant B also received no supports and was not offered any.

Participant D said she was offered no supports but also felt she didn't need any supports. She believes that it is her own condition which she must learn to manage by herself. The main thing she struggled with in school was concentration but she said she can't think of anything the school could do to help with that.

Similarly, Participant E said she received no supports but also didn't look for any because she didn't really want them. "*At the time, I felt I didn't really need it, but I wasn't offered anything either*". She also suggested at that age most students just want to fit in with their peers so they often don't want to do much different things than their classmates.

However, participant C had a more positive experience. During 6th year she received extra classes similar to grinds after school because she missed so many days of school. She choose the two subjects she wanted to do better in, so she received two extra hours of maths a week and 1 hour of French. The teachers would stay after school to do this with her, which she

found really helpful. The research then asked if this support was offered to her or if she asked for this? "*It was a mix of both, I had missed so many days of school and mom was looking into grinds when she discovered there was actually a facility available*.

Participant F received the same support service. She received 4 hours a week paid from the state with the teachers of her choice who agreed to the program. "*I used to see my geography teacher after school for 2 hours a week and my maths teacher during religion blocks*".

Participant G received no additional service but did acknowledge that her teachers were also very understanding if she came to school without work done or missed classes.

5.4 State Exam Supports

Participant A received no supports for exams but didn't ask for any as he didn't feel it was necessary

Participant B received her own room for her Leaving Cert but she said "*that was mostly requested by other student's parents so that I wouldn't interrupt their child's exam"*. She also said if she had a seizure she would be entitled to extra time. "*I had a seizure during English Paper 2, so I was out for about 15 minutes between recovery time and everything, so I got that 15 minutes extra at the end. Nothing more."*

The researcher then asked if she was able to concentrate after the seizure? "*If I have a still seizure I'm fine afterwards, but if it's a moving one I could sleep for more than 24 hours after. I was very lucky I only had a still one during the exam."*

Participant C also had her own exam centre. Another additional service was offered to her, "because *most of my problems were in the morning it was set up that a teacher would collect me from home and accompany me to school*", so if she had a seizure in the morning a teacher would bring her to school later that day and ensure she wasn't texting or asking anyone about the paper. The same teacher would then supervise her in her own separate room. She was allowed to choose herself which teacher she would like to do this. Thankfully she felt lucky not to have any problems or seizures during her exams but she was still very grateful that this service was offered and it made her less nervous about having a seizure.

Participant D was offered additional time, a reader and a separate exam centre for her Leaving Certificate but she ended up not needing any of them.

Participant E also did her Junior Certificate in a separate room because she had a seizure the day before the exams began so her Mam requested this. However, she didn't need it for her Leaving Certificate. She was also offered extra time but she didn't use it. Luckily she had no seizures during her exams but she said if she did there is no way she could have continued to do that exam that day. She said during Christmas and summer tests at school her teachers were very understanding and often allowed her to do the exam at a different time, if she wasn't feeling up to it when the rest of the class were sitting it. "*It wouldn't be fair to ask students to finish an LC exam on the same day they had a seizure because you would be so tired after it*". She said it would be impossible to sleep for a few hours then wake up and try to sit the exam. "*That is completely unfair to expect someone to do that".*

Participant F also had a separate exam centre for both the Junior Certificate and Leaving Certificate, she was also able to choose the teacher she would like to supervise her, which she

found helpful as she said "*it is important for me to be with people I know well for things like this… Feeling comfortable with my supervisor would calm me more, decreasing my chances of having a seizure".* She also mentioned the DARE program which she said helped also to reduce her nerves as they would have helped her to get her first choice in college if she hadn't had enough points. However she didn't need this support but was still glad to know it was there.

Participant G said she was allowed to take her Pre-Leaving Certificate exams in her own centre but for reasons she does not know, she sat her actual Leaving Certificate exams in the same centre as everyone else. However, the rooms were maximum of 30 students so she said it wasn't too much of an issue.

5.5 Stigma and Prejudice

Participants were asked if they ever felt they were treated differently in school because of their epilepsy? From teachers, staff or other students.

Participant A said that largely no, he didn't feel he was treated too differently. However he said yes on a more personal level "*you know when you're in your teens, and you're going out and exploring things, I had to be very careful when the lads were going out for a few pints, I had to draw back a bit so I suppose I did feel a bit on the outside*" . The social side of school is a big aspect and he did feel that his epilepsy may have held him back bit from making new friends and "*fitting in*".

Participant B felt that staff took pity on her. She said this was good in some cases when she didn't have homework done or was late for class, they understood, but she also at the same

time questioned if sometimes she was being marked easier. Participant B felt that her experience in her first school was so negative because nobody understood what epilepsy was. The teachers and head of the school "*thought it was dramatic for other students to witness- which is true. But I don't think they really took my perspective into account"*. She explained it was very tough among other students too because they didn't understand it properly and many of them thought she was *"attention-seeking".*

However in her second school, she says her principle was excellent and he went around to every class at school and told them "*there's a girl who falls over sometimes and if you see her don't touch her, once there is somebody with her, then you just mind your own business and keep going"*. She found this was very good as people were more understanding and didn't make such a big fuss about her having a seizure.

Participant C said that her teachers were very understanding and if they treated her differently is was only "*in a positive way"*. Once she was diagnosed the principal called a meeting with all teachers to explain her condition to them. She said the teachers were very understanding of the things she couldn't do and never questioned her if she didn't have homework done or was late to class. She said she was definitely treated differently by other students who "*were kind of tip-toeing around me*". People who picked on her before were actually much nicer to her after she was diagnosed.

Participant D and E didn't feel they were treated different.

Participant F also said that she was only treated differently in a positive way. "*If I was treated differently, it was only because my teachers cared about me".*

Participant G said if she was treated differently then she didn't notice. She emphasised that her friends were "*tremendously supportive*" and did all they could to help her keep up with schoolwork.

5.6 STRESS

Each participant said that stress was a contributor to their seizures. They said as a student in general facing the Leaving Certificate exams the pressure is huge but if you add the anxiety about having a seizure during these exams the pressure is doubled. Participant B said "*my biggest worry for the LC was if I would have a seizure, especially for the oral because I just felt like they would not judge you but maybe take pity on you like mark you easier or something".*

Participant F said the part of her life that causes most stress for her is exams and assignments. "*I have never gone through an exam session without getting seizures, since first year Christmas tests in school, up until now in college exams"*

Participant G said stress is undoubtedly a contributor to her seizures. She explained her epilepsy was triggered in 3rd year due to the build-up of anxiety in her life. She said the stress of having epilepsy was at its worst in 6th year, and she was extremely worried about having a seizure during her Leaving Certificate exams. *"If this fear had materialised it would have meant an immediate negation of that exam and I would have been forced to repeat the LC".*

5.7 STUDENT RECOMMENDATIONS

The participants were asked about what services they feel should be developed and implemented in schools to support current and future students with epilepsy.

Participant A felt that extra time should be implemented for students who have a seizure, he suggested even sitting an alternative exam on an alternative day. However also highlighted that "*State Exam rules do seem to be quite rigid".*

Participant B felt that raising awareness in schools would benefit a lot. She suggested an information talk for both students and teachers so they would have a better understanding and not be afraid of it. She also recommended a Special Needs Assistance, which could help out when they missed work in school. Having somebody close by that understands the condition who could help whenever necessary.

Participant C said that when she was in Transition Year they had an information talk from Epilepsy Ireland. They spoke to the students about what epilepsy was, different seizure types, what to do if they see someone having a seizure and simple first aid techniques. She felt this was very beneficial and should be done in all schools. She also suggested the schools having an emotional counsellor or therapist to speak to when students are first diagnosed. She said "It *is very hard to adjust, going from being perfectly healthy to being technically disabled".* She realised after that, the way she tried to cope with it, was by pretending it wasn't happening and she feels that if she had somebody to talk to in school or was taught about some type of coping method, then maybe it would have made the adjustment easier. She also suggested additional training for teachers in relation to different health problems. Finally, in relation to exams she said all the supports she got were great. They really helped to put her

mind at ease so she wasn't panicking about having a seizure during an exam, and it ruining everything. She thinks if everyone was offered the supports she got in her school then that would be a great step.

Participant D was unsure about what supports could be implemented in school but she spoke about the DARE program that exists in universities. She recognises that this is a great initiative and is definitely a help for students with epilepsy, however it only exists in universities and not in IT's. She suggested this program or something similar should be implemented in every college which may reduce the pressure. She stated that "only *1 in 3 people in Ireland with epilepsy attend 3rd level education*".

Participant E feels that at that age most people just want to fit in so she said it really depends on the student themselves. She said that for Exams, students who have a seizure during or before an exam should definitely be allowed to sit an alternative exam on an alternative day. "*Everybody wants to have as much as a normal life as possible and go to college, but if they have a seizure during an exam and are not provided with the resources to repeat the exam on a good day then those opportunities are taken from them".*

Participant F said there is nothing more she can think of. "*I am very happy and grateful with the supports and emotional support I received in my specific school*".

Participant G feels that in general, schools deal with epileptic students quite well. However, she would have really liked her own exam centre for the Leaving Certificate and was upset she didn't receive this. She also thinks it would be a good idea if more students and teachers

were informed about epilepsy and what to do in the case of someone having a seizure at school.

6 DISCUSSION

6.1 SCHOOL ATTENDANCE

This research has shown that epilepsy can often have an effect on a student's attendance at school. Several of the participants in this study reported that they missed many days of school. For a child at either primary or secondary level, missing a lot of days at school can have a crucial effect on their educational progress and outcome. According to Zinshteyn, 2017 "missing just two days a month of school for any reason exposes kids to a cascade of academic setbacks, from lower reading and math scores….to higher risks of dropping out of high school" (Zinshteyn, 2017).

6.2 SCHOOL PERFORMANCE

In general most participants in this study said they experienced no additional learning difficulties along with their epilepsy. These participants did not allow for their epilepsy to hold them back and each one of them has gone on to third level education. However, the literature review identified that many students with epilepsy have learning difficulties that may go "unrecognised and unsupported" (Epilepsy.org.uk, 2017).

One participant did say she experienced attention and concentration problems which was one of the learning problems identified through literature (aboutkidshealth.ca, 2016). In the survey that was carried out on parent's opinions on, and experiences of provisions for children with epilepsy in the Republic of Ireland, the highest area of educational difficulties

was concentration. The participant in this study however felt that this learning difficulty was a personal problem and never looked for any help from her school.

For the student who experiences absences as part of her epilepsy, she concludes this definitely had an impact on her performance in school. She would often have absences during classes and therefore missed a lot of work even though she was present in school. "The more seizures a child has, the more pieces of information they will miss. For example, if a child has hundreds of short absences in a day, they will miss many little bits of information. This will make gaps in their learning" (Epilepsy.org.uk, 2017).

School attendance has a direct link to school performance. This research has already shown that attendance was an issue for many students with epilepsy, and many confirmed they were often late to school due to morning seizures. This in turn will have a direct impact on their school performance as they are missing out on work. Most participants also said that they often didn't do their homework because they were too tired or had a seizure in the evening.

6.3 SCHOOL SUPPORTS

A law should be implemented to ensure that each student with epilepsy receives the same quality of care and support, irrelevant to which school they attend. Each school should have the same action plan for students with epilepsy. However, it is clear this is not the case.

A prime example of this inequality between schools was highlighted by participant B who had the experience of two different schools. Although moving schools was beneficial for participant B as she was treated better in her second school, this did put financial strains on her family as the first school was public and the second was private.

A law similar to the Children and Families Act 2014 in England which was outlined in the literature should be developed for Ireland. It should include a plan to ensure all teachers and staff have an understanding of epilepsy and each child should have an individual healthcare plan.

The State does provide extra teaching hours for students with epilepsy who have missed many days of school. However, only 2 participants in this study even knew this service existed.

Although not all students with epilepsy will need additional support in school, it should still be offered and made available to them. In this way, they will feel less nervous about having a seizure and more comfortable in school.

6.4 Exam Supports

It was hopeful to see that most participants were offered or were aware that they were entitled to their own exam centre for State Exams. Although not all of them used this service, those who did confirmed that it really put their mind at ease and they were less worried about having a seizure during an exam.

The two participants who received extra tuition hours were very grateful for this service and expressed great gratitude to their teachers who provided this teaching. This service is a great support for students with epilepsy, especially those who have missed a lot of school or may not be able to afford grinds. However, the other students were not offered this service or were not aware of its existence.

Most participants were offered extra time, for those who didn't have a seizure they didn't need the extra time. However, they said if they were to have a seizure during the exam, extra time afterwards would not be much benefit to them. They explained that following a seizure they would be unlikely to be able to fully concentrate and answer the questions to their best ability. For participant B who experienced a still type seizure during her Leaving Certificate, she only received the time she was out for which was 15 minutes. She said that she was lucky it was a still seizure because she can function perfectly again after these but she said if she had a moving seizure there is no way she could have completed this exam. This is similar to Sean Fenton's story outlined in the literature review who expressed his concerns for sitting his Leaving Certificate this year. He explained that during his Junior Certificate he had many seizures and was unable to finish all the papers.

It can be concluded that the supports provided may be enough for some students with epilepsy, but for many other students with epilepsy they are nowhere near enough. As Dr.Senior said "for some, seizures make the Leaving-Certificate process insurmountable, which limits their college and life choice. This is questionable in terms of equity and rights" (The Irish Times 2017).

6.5 Stigma and Prejudice

It was very positive to hear several students didn't feel they were treated differently because of their epilepsy and of those who did, many referred to it in a positive way. The majority felt teachers were understanding and kind towards them. It is essential for teachers, students, parents and staff to be informed about epilepsy and what exactly it is. This way they will be more understanding towards students and won't judge them based on misconceptions and misbelief.

Dr Veronica Lambert's study which was outlined in the literature review, highlights the fear some children have about telling others about their epilepsy, due to the perceptions people have about epilepsy. Speaking about the study, Dr. Veronica Lambert, commented; "t*here are so many different social groups informing our perception of epilepsy, be it from our own families, or from friends, colleagues or classmates. Living with epilepsy requires a collective level of acceptance, openness and understanding from all such social groups that evidently we have not achieved yet in Ireland.*"

She added:

"*To overcome obstacles to understanding, it is apparent that we need to move beyond promoting epilepsy awareness through providing information, to creating social spaces that encourage open dialogue between children with and without epilepsy and others – for example, parents, health professionals and teachers – so they can demystify the condition and engage in critical debate about stigmatisation*." (O'Toole et al, 2016)

Participant B definitely experienced this cruel prejudice in her first school and this was mainly due to a lack of knowledge among other students. The other students didn't know about epilepsy or what to do if she had a seizure and they were, therefore, afraid of it.

This misinformation has stimulated prejudice and discrimination against people with epilepsy, has caused them to be stigmatised and ostracised, and has compromised their ability to work and have an active social life (Bandstra et al., 2008; Eadie and Bladin, 2001; Jacoby et al., 2004, 2005a, b)

Participant A identifies with the challenges of having an active social life which is a big part of schooling. He feels that his epilepsy held him back from fully participating in social interactions.

De beour 2010 believes seizures can often have physical, psychological and social consequences; they can cause misunderstanding, fear, secrecy, stigmatisation and social isolation. The problems people with epilepsy encounter daily are not related to the severity of the condition but stem from the concepts of epilepsy as held by the public.

6.6 STRESS

The participants in this study concluded that stress is no doubt a contributor to their seizures. Stress and anxiety are well-established triggers for seizures among people with epilepsy, and studies have shown that reducing stress may lower seizure risk for those with the condition. While neurologists recommend that patients with epilepsy avoid stressful situations as a way of avoiding stress-induced seizures, it is not always possible to do so (Whiteman & Whiteman, 2017). When it comes to the Leaving Certificate many students in general are under severe stress. They are expected to memorise large amount of information and then reproduce this in the exams. For many students, they feel that these exams will determine the rest of their lives as they are aiming to get the highest grades they can, and get their first option on the CAO. It is easy to understand how this type of pressure would cause a lot of stress and anxiety among students, but add the fear of having a seizure during one of these exams, inevitably, this stress becomes increasingly worse.

Peter Murphy the Chief executive of Epilepsy Ireland says "*Epilepsy is a very individual condition that affects different people in different ways, but in the vast majority of cases a seizure during or before an exam will prevent the students from performing anywhere near their best on the day".*

6.7 RECOMMENDATIONS.

The main aim of this research project was to discover what supports are available and what supports are lacking for students with epilepsy in Ireland. The participants in the study made some recommendations they feel should be implemented to improve the quality of life for epileptic children in schools.

The recommendations included:

- Information Talk: The students recommended an information session to inform other students and teachers about epilepsy. This could be run by a voluntary organisation or by the school itself. This should include information about different types of seizures and what to do when someone has a seizure. This type of information session was conducted by Epilepsy Ireland in participant C's school and she felt it was very beneficial and should be implemented in all schools.

- Teacher Training: The students felt teachers should really be trained in the area of epilepsy and other illnesses. This could be incorporated into their undergraduate training, during a course day or could be done online. A free online course that teachers could log on to if they had a child in their class with epilepsy and get training on what they can do to help would make a big difference.

- Counsellor: A counsellor was recommended to have somebody to talk to in school especially when first diagnosed. Having somebody to talk to openly about their epilepsy would improve their coping strategies. This may also be a good service to have available coming up to exams, the students could go to the therapist if they were feeling stress or anxiety and talk to them about it.

- Special Needs Assistant: An SNA was recommended to help students who experience absences and zone out during class. Some students even mentioned falling asleep during class. For this reason they can often miss information being taught in class. An SNA could help the student keep up with classwork and homework and fill them in on anything they may have missed.

In relation to exams, the following recommendations were made:

- Extra time: Almost all students felt confident that if they had a seizure during an exam they should be entitled to extra time in the exam.

- Alternative exam: Students felt that if they had a seizure during an exam they wouldn't be able to complete that exam to the best of their ability. They therefore feel it would be fair if they could sit an alternative exam on an alternative day. They feel that asking a student who has had a seizure to complete an exam that day is completly unfair and near impossible for many students.

- DARE: The DARE program was recognised as a beneficial program. However the student’s believe it should be implemented in every college and not just universities.

- Reasonable accommodations: There is a program in the UK that allows different illnesses and events to be taken into account when an examiner is correcting an exam. For example if the examiner knew a child had a seizure during an exam, they could receive an extra

5%. If something similar was introduced here this might take away some of the anxiety students have.

- Rest breaks: The students feel they should have the chance to take supervised rest breaks during an exam, if they are feeling tired or unwell. This may prevent them from actually having a seizure.

7 CONCLUSION

This study has succeeded in answering the key aims and objectives. It has shown that epilepsy can have a great effect on a student's experience in school. It has identified that epilepsy can often cause students to be absent from school, and in turn this can have an effect on their school performance. It also recognised that some students experience difficulties with learning as a result. After reviewing the literature and policies, stigma was a key theme that emerged. However participants in this study didn't feel greatly affected by this stigma. The students in this study who felt they were treated differently said it was only in a positive way. There was limited supports offered to students during school but not all of them believed they needed any supports. Most students confirmed that stress was a largely contributing factor towards their seizures and therefore increases their anxiety before exams. Some students received additional support for exams such as their own exam centre. However, it was identified that there is a lack of knowledge and understanding about epilepsy in school and these students are therefore not fully supported. This study has identified a number of recommendations to improve the lives of current and future students with epilepsy. These recommendations are an invaluable asset to this study as they have come from the students themselves.

However, it must be recognised that this was a small scale undergraduate study, with limited time and resources. The results found from the 7 participants does not accurately represent the entire population with epilepsy in Ireland. Therefore, it would be recommended to conduct further research into this area. Perhaps interview more students, along with parents and teachers. Further research could also incorporate both qualitative and quantitative methods.

Overall, it can be seen that epilepsy affects students and therefore some changes must be made to accommodate the challenges these students experience in our education system. In order for these students to gain full participation and access to education, we must first begin by raising awareness and understanding of epilepsy. Once this is done some supports must be implemented in order to achieve a truly egalitarian education system in which all students receive equal opportunities.

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APPENDICES

Interview Questions

Male or female?
Age?

1) Can you briefly describe the type of epilepsy you have?
2) When were you diagnosed?
3) Can you tell me about your experiences as a student with epilepsy in school?
4) Did you miss many days of school due to your epilepsy?
5) Did you ever experience any additional learning difficulties?
6) Did you receive any additional help, support or resources at school?- what were these
7) In relation to Sate exams, were you provided with any additional support?
8) Did you ever feel you were treated differently because of you epilepsy? -from other students, teachers or staff.
9) Do you think stress is a contributor towards your seizures?
10) Is there any supports that were not made available to you at school that you think should be implemented to support current or future students with epilepsy?

INFORMATION SHEET

Purpose of the Study: As part of the requirements for Social Science at UCC, I have to carry out a research study. The study is concerned with students with epilepsy, their experiences and learning at school, with a particular focus around exams

What will the study involve? The study will involve conducting 6-8 interviews with people with epilepsy (18+) who have had experience in the Irish educational system. The questions will involve research into the students experiences at school, what provisions were provided and also what additional help could be developed to improve the school experience for other student's with epilepsy.

Why have you been asked to take part? You have been asked because you are over the age of 18, have epilepsy, and also went to school and participated in state exams.

Do you have to take part? No– participation is voluntary. Participants will have to sign a consent form before the interview. Participants may keep a copy of this information sheet also. Participants also have the option of withdrawing before the study commences (even if they have agreed to participate) or discontinuing after data collection has started. If for any reason the participants decides after the interview that they don't want their data to be used they can contact the researcher up to 2 weeks after the interview and the data will be destroyed.

Will your participation in the study be kept confidential? Yes. The researcher will ensure that a persons' identity will not appear in the thesis. Any extracts from what you say that are quoted in the thesis will be entirely anonymous.

What will happen to the information which you give? The data will be kept confidential for the duration of the study, available only to me and my research supervisor. It will be securely stored by a password protected data base at UCC. On completion of the project, they will be retained for minimum of a further ten years and then destroyed.

What will happen to the results? The results will be presented in the thesis. They will be seen by my supervisor, a second marker and the external examiner. The thesis may be read by future students on the course. The study may be published in a research journal. The research results will also be presented to Epilepsy Ireland and the Community-Academic Research Links (CARL) to discuss the study finding, to explore actions / implementation plan arising from the study and to discuss future public presentations and publications related to the study.

What are the possible disadvantages of taking part? I don't envisage any negative consequences for you in taking part. However, if your school experience was negative, it is possible that talking about your experience in this way may cause some distress.

What if there is a problem? At the end of the procedure, I will discuss with you how you found the experience and how you are feeling. If you subsequently feel distressed, you should contact the researcher, Epilepsy Ireland, or your GP.

Who has reviewed this study? Approval has been given by the Social Research Ethics Committee of UCC.

Any further queries? If you need any further information, you can contact me or my supervisor:

Sarah Cooke,
114316501@umail.ucc.ie
0879876711

Lorna Kenny
lorna.kenny@ucc.ie

If you agree to take part in the study, please sign the consent form overleaf.

CONSENT FORM

This consent form is designed with qualitative research in mind. Where quantitative methods are used, issues such as quotations and audio-recording do not arise.

I……agree to participate in Sarah Cooke's research study.

The purpose and nature of the study has been explained to me in writing.

I am participating voluntarily.

I give permission for my interview with Sarah Cooke to be audio-recorded.

I understand that I can withdraw from the study, without repercussions, at any time, whether before it starts or while I am participating.

I understand that I can withdraw permission to use the data within two weeks of the interview, in which case the material will be deleted.

I understand that anonymity will be ensured in the write-up by disguising my identity.

I understand that disguised extracts from my interview may be quoted in the thesis and any subsequent publications if I give permission below:

(Please tick one box:)
I agree to quotation/publication of extracts from my interview
I do not agree to quotation/publication of extracts from my interview

Signed: ……. Date: ……..
PRINT NAME: …….