“An investigation into the effects of an epilepsy diagnosis on an individual’s life and life decisions”

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STATEMENT 1

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Abstract

Epilepsy is a common disease that is found in 2% of the population, affecting all generations (Howard et al., 2014). When an individual becomes faced with an epilepsy diagnosis, their body undergoes specific physical and psychological changes (Schachter, 2003). The fundamental change in which the individual will experience is the change within their identity. This change in identity may have a large impact on a person’s life physically, socially and mentally (Nubukpo et al., 2004). This study has examined how an epilepsy diagnosis may impact an individual’s life and identify and discuss the changes that may occur as a result of diagnosis.

Semi-structured interviews were conducted on four volunteer participants whom agreed to take part in the study. Once the data had been collected, a thematical analysis was conducted. This method considers all available research on the topic critically appraises the research for validity by measuring the findings of data and discovering mutual themes to produce results. The researcher created a number of different themes that were apparent in the review of the discoveries of the study. These themes include: the effects on social well-being, impact on the family, family support system and physical changes, employment, education and sporting activity. This study delivers a variety of recommendations for government, organisations and future researchers. It recognises that there is a need for additional research into the ways individuals with epilepsy cope with everyday life.
Chapter one

Introduction
Introduction

This study is an in-depth consideration of the “effects of an epilepsy diagnosis on an individual's life and life decision”. This study will examine the psychological and physical changes to which an epilepsy diagnosis may create and provide an account as told by four epilepsy patients of their experiences after their diagnosis.

Epilepsy is one tendency to have recurrent seizures. It can affect anyone, at any age and during any time. Epilepsy is one of the most common serious neurological conditions. Epilepsy is not a single condition; research has indicated that there are 40 different forms of the condition. There are at least 40-50 different seizure types and individuals can have from one to several of them (Fisher et al., 2005).

There are approximately 3500 individuals within the United Kingdom (UK) with epilepsy (Brown & Betts, 1994). Chadwick (1988) suggests that 70-80% of these cases are controlled by anti-epileptic drugs. As a result, O'Donoghue et al. (1998) suggests that an epilepsy diagnosis can create negative implications resulting in difficulties being created within individual lives. These difficulties being: emotional, psychological, social and behaviour wellbeing.

While undertaking literature searches the researcher noted that all evidence was conducted from secondary sources rather than being a primary source, the individual themselves. The researcher found that the literature review was structured in sub groups. As such, the researcher, structured the literature review in the same sub group. The sub groups include the process of diagnosis, psychopathology and social interaction, social stigma/stereotypes of epilepsy and the creation of depression within epilepsy. Alongside this, a study taken by Schneider and Conrad (1983) examined how individuals with epilepsy adjusted to the condition and from this it was suggested that many individuals did so much more effectively and successfully than others. It is suggested that when epilepsy is poorly controlled it can create increased levels of anxiety and depression (Pullianen et al., 2000). In turn epilepsy can create lower levels of self-esteem (Baker et al., 1997) and low levels of independence, resulting in social problems and social anxiety (Thompson & Oxley, 1989).
As a result of previous research, the objectives of this study are to investigate and examine the primary source in respect of epilepsy and the psychological effect epilepsy has on the individual. The purpose being to evaluate the research to broaden the researcher’s knowledge of the topic. Therefore, to conclude, the aim of the research is to discover the impact of a diagnosis and the effect it has on the individual life.
Chapter two

Literature search
**Literature search**

According to Bryman (2008) a literature review, is a detailed exploration of a range of different literature types to obtain a quality literature which is relevant to the topic of the research question. To do this, several different search methods were used for the literature search using a wide range of different resources, for example; books, journals, public consultations etc. Using different search methods enables the possibility of collecting a range of high quality resources that may have been missed if only a single search method was used.

There are several different benefits of completing a literature search, one being that it can expose gaps in current research (Knopf, 2006). Knopf (2006) also identified that completing a literature search can enable the researcher to provide significant results from the intended research discovered, in the context of what had previously been researched. Knopf (2006) also suggests that literature searches are useful when developing research as it can validify the research in the topic and highlight key areas.

The search databases chosen for this literature search were Met Search, held by Cardiff Metropolitan Electronic Library and Google Scholar. The reasoning behind the selection was based on the individual strengths that each of them hold. A benefit of using Met Search is that the search can be redefined, so that it only includes and excludes the criteria in which is needed, such as certain scholarly and peer-reviewed resources. Google Scholar is another valuable database as it can provide different results from Met Search. The D Space was also utilised as it had the potential to guide good quality references relevant to the topic.
Chapter Three

Literature Review
Literature Review

This chapter will explore and analyse the literature that is already presented about epilepsy. To explore the impact of an epilepsy diagnosis on an individual’s life and their life decisions, it is important to begin with the key terminology.

Diagnosis

Epilepsy is a common chronic neurological disorder (Leonard & George, 1999). This chronic disorder consists of seizures caused by abnormal electrical paroxysmal discharges. Similar to this, Banerjee et al. (2009) defines epilepsy as a condition categorised by a consistent, for example two or more epileptic seizures, which are unprovoked with no recognised cause. Epilepsy is a unique and unpredictable disorder (Jacoby et al., 2002). Chadwick (1998) suggests that epilepsy has an occurrence of around four in ten in a thousand individuals. In the UK, it is suggested that there are approximately 3500 individuals with epilepsy (Brown & Betts, 1994). Research conducted by McLin and Williams (1992) suggests that within the United States there are roughly 2.5 million individuals with epilepsy. Sander (2003) states that within Europe it is estimated that approximately 0.9 million children and adolescents are living with active epilepsy. All definitions of epilepsy are related to the concept of seizures, resulting in this being the major characteristic of the condition.

Individuals may develop epilepsy because they follow a genetic tendency, inherited from one or both parents; or due to a genetic tendency that is not inherited, but is present in an individual’s genes. Epilepsy may also commence due to a structural change in the brain. Such as abnormal brain development, damage caused by a brain injury or infections such as meningitis, a stroke or a tumour (Epilepsy Society, 2016).

Fisher et al. (2005) suggests that epileptic seizure is the clinical manifestation of “abnormal excessive or synchronous neuronal activity in the brain” (Fisher et al., 2005, pp. 6). Alongside this Sander and Shorvon (1996) suggests that a single epileptic seizure occurs in up to 5% of the general population. Chadwick (2006) underlines that just one seizure attack cannot identify if a patient’s attacks are epileptic in nature and because of this, other considerations must be addressed.
Although the beginning of seizures is unpredictable, there are several different stimuli's which may initiate seizures. Miller (1994) proposes that these stimuli's include: emotional and psychological stressors, such as sexual activity; prescribed or recreational drugs; and hyperventilation. Identification of these stimuli factors are useful as intervention therapies can be focused towards them, which in turn, may support the individual in avoiding or controlling such factors, which will result in dropping seizure occurrences (Goldstein, 1990). It is apparent that 70-80% of epilepsy cases, use anti-epileptic drugs to control seizures (Chadwick, 2006). There are many different anti-epileptic drugs that are used to treat epilepsy. However, when using anti-epileptic drugs individuals must take caution as it can result in individuals having a variety of toxic and dosage side effects (Chadwick, 2006) for example hyperactivity and depression (Trimble, 1996).

O'Donoghue et al. (1998) suggests that an epilepsy diagnosis may have many negative implications and can often cause difficulties with the individual. These difficulties are identified as emotional, psychological, social and behaviour wellbeing. Schneider and Conrad (1983) examined the way in which people with epilepsy attuned to their condition, and reported that some individuals did so much more effectively and successfully than others. Sansder (2005) suggests that an epilepsy diagnosis can affect individuals within a range of ages with increased rates of epilepsy being high during early childhood, and levelling out during early and middle adulthood (Forsgren et al., 2005). Therefore, individuals fear being diagnosed and fear being stigmatised for having a disability, and this anxiety remains with them throughout life, fearing that they are going to be unsuccessful in life. This is evident from the research gathered above.

Eklund (2003) suggests that epilepsy provides an example of concealable stigmatised identity; this is due to individuals having the capability to hide it from others. It is only during the period of a seizure or cues of the epilepsy condition, to which epilepsy becomes visible to others (Eklund, 2003). Scambler (1989) suggests that restricted knowledge within the context in which those living with epilepsy conceal or disclose their diagnosis to others.
**Psychopathology and Social interaction**

An epilepsy diagnosis and seizures can cause difficulties within individuals lives. These difficulties can be associated with psychological and social problems. The main difficulties challenged by individuals with epilepsy is the social problems, this being stigma and stereotypes, resulting in a cross-cultural problem (Hills & Baker, 1992). Raeburn and Rootman (1996) identifies that social well-being is a concept that is embedded in definitions of quality of life, health and social inclusion (Valentine et al., 2005).

A study taken by Schraegle and Titus (2016) on health-related quality of life of children and adolescents with epilepsy, suggested that around 20-60% of adolescents and children with epilepsy also experience some form of psychopathology. The risk of suffering with depression and anxiety is increased in youth and usually goes untreated. This has been linked with a negative quality of life. The study highlighted that there is an increased risk to youths experiencing psychopathology symptoms, usually presented as depression and anxiety (Schraegle and Titus, 2016) The study revealed no link between internalising psychopathology in youths with partial and general onset of seizures. Furthermore, the study indicated that depression in youths suffering with epilepsy had a noticeable effect on health-related quality of life. Youths experience emotional problems, anxiety and lower intellectual level, more so than children.

Biological changes in adolescence is a time of significant transition, for example development of peer relationships and changing oneself to certain situations. Healthy peer relationships can be challenging for individuals, with a successful transition leading to a healthy identity formation. However, conversely difficulties with this can cause a direct impact on the adolescent's quality of life (Austin, 2007).

Research conducted on the quality of life in comparison to adolescents with epilepsy, diabetes and asthma, identified a reduction in the quality of life in those with epilepsy. This was addressed with the individual's relating back to their own personal experiences.

Furthermore, using a method for research that focuses on adolescents’ descriptions and definitions is essential. Previous studies have used pre-existing
scales and methods used with adults. The difficulties with this has been recorded in different studies. The studies found within this area have failed to consider developmental issues, despite the significant transitions made as the adolescent progress towards adulthood (McEwan et al., 2004). McEwan et al. (2004) used a qualitative methodology gaining the information from focus groups. Their study showed two main themes; identity formation and epilepsy related variables. These themes were addressed as the peer acceptance development of autonomy, school related issues of the future, and epilepsy as part of me. These were embedded within normal development as a major factor presenting additional challenges to the successful completion of these developmental tasks. However, this study unlike previous studies did not show any difficulties with academic studies.

Pullianen et al. (2000) states that poorly controlled epilepsy can create increased levels of anxiety and depression, resulting in lower levels of self-esteem, low levels of independence which in time creates social problems and social anxiety (Thompson & Oxley, 1989). These impacts can also influence an individual’s employment prospects and create lower rates of marriage, together with the restrictions placed on driving and social stigma. Dell (1986) argued that, even in contemporary worlds, stigma remains limiting to the quality of life of those affected by it. Dell (1986) observation has been noted in research linking stigma to epilepsy, resulting in increased rates of psychopathology and reduced social interactions and social capital of those with the condition.

**Social stigma/stereotypes of epilepsy**

Goffman (1963) defines epilepsy as “an attribute that is deeply discrediting” (Goffman, 1963, pp. 12). Andermann et al. (1995) suggests that individuals with an epilepsy disorder are likely to be marginalised within their societies. MacLeod et al. (2003) identified that historical epilepsy has a particularly poor reputation with regards to stigma and social exclusion, and is commonly reported by those who are within both the developed and developing countries (De Boer, 2010). Baker (2002) conducted a large-scale study in the 1990’s with individuals from Europe and showed that more than 51% of 5211 adults reported feeling stigmatised due to their epilepsy condition. In addition to this, a survey conducted in 2012 by Epilepsy Ireland, echoed the studied by Baker (2002), showed that
from a sample of 464 adults living with epilepsy, it was reported that 52% experienced stigma because of their condition. In line with these finding Hifanoglu (2009) cited in Aliobhe et al. (2015) undertook a study in Turkey, which identified that from a population of 220 children with epilepsy, 41% of children aged 8-17 years stated they felt stigmatised by their peers due to their epilepsy diagnosis. World Health Organisation (WHO) (1996) and Reynolds et al., (2001) reported that there were some improvements made within the public sector to change individual's perceptions of epilepsy; this was due to public education to bring epilepsy out of the shadow

Elliot et al. (2007) suggest that childhood and adolescence are crucial periods of identify formation and self-definition. Within this stage of life children and adolescence follow normality as a supreme priority and strive to receive peer acceptance. Dell (1986) suggests that epilepsy is a unique and unpredictable disorder, with changing symptoms, that can often cause embarrassment and distress for the individual. Over the year's epilepsy has remained a stigmatising medical condition. Jones et al. (2001) proposed an alternative model for understanding stigma, which involves six different dimensions. Such dimensions include concealability and course of the mark, with these dimensions making up the whole scope of the epilepsy stigma. Crocker et al. (1998) argued that visibility and controllability are seen to be the vital dimensions of stigma. Scott (1972) argues that circumstances are stigmatising just as much as they threaten the accepted social order.

Trostle (1997) stated that seizures may be implied as a “uniquely dangerous to normal social integration, due to representing human weakness and unpredictability” (Trostle, 1997, pp. 63). Moving forward Bagley (1967) implies that the persistence of theories of epilepsy are based in “amomic terror” (Bagley 1972, P.74). Scrambler (1984) stated that individuals with epilepsy are a twofold threat within the social order. Goffman (1963) highlighted stigma by explaining that it arises from a conceptualization by society of what constitutes differentiation or deviance and the subsequent application of rules and sanctions against the person labelled. Goffman (1963) also suggests that an individual who is stigmatised possesses “a trait that can obtrude itself upon attention and turn
those of us whom he meets away from him, breaking the claim his other attributes have on us” (Goffman, 1963, pp. 22).

Scambler (1989) suggests that due to this, even those whose epilepsy enters long-term remission endure to live with the label “epileptic” and in Goffman’s disputes, a “spoiled identity”. A research study taken by The United Kingdom Medical Research Council Study of Antiepileptic Drug Withdrawal, examined the quality of life of individuals who were within years of their epilepsy diagnosis. The research indicated that overall, only a small minority, 14%, reported any sense of stigma. Moving on studies such as Beran et al., (2008) have suggested that high levels of individuals reported they felt and endorsed stigma. Trostle (1997) enhanced the importance of the feelings of stigma in relation to being problematic, thereby implying that individuals with epilepsy are countable for their own personal lower levels of achievement.

Jing Jin et al., (2008) suggested that during the 1990’s there became an interest into the systematic assessment based on the health status of an individual with epilepsy. The research revealed that high levels of anxiety and depression are among individuals with epilepsy. Jacoby (1997) examined quality of life in 607 people whose epilepsy was in remission, using a three-item measure of felt stigma adapted from the work of Hyman (1971).

Although is it suggested that epilepsy can provide troubling and unpredictable symptoms, most individuals with epilepsy, require little assistance of care and live an independent life. Kokkonen et al. (1997) suggest that around 80% of individuals with epilepsy use regimes of anti-epileptic drugs to control their seizures. Whereas, conversely Sander and Shorvon, (1987) propose that it is still estimated that between 80-90 thousand people in Britain have chronic or severe epilepsy, of which many will need some form of support throughout their life.

**Depression and anxiety**

Adolescence is a time of significant transition in terms of biological changes, alteration in one’s role and development (Coleman & Hendry, 1999). Successful completion of these tasks is vital for healthy identity formation. Difficulties with identity formation directly impact on the adolescent’s quality of life. For example, “the individual’s evaluation of the quality of their lives as it relates to their own
personal expectations" (Andelman, 2000, pp. 17). Problems can result in depersonalisation and subsequently lead to low self-esteem, loneliness, depression, anxiety and behavioural problems (Leonard & George, 1999).

Epilepsy, anxiety, and depression are all common disorders. Due to this the conditions cohabit in a significant number of individuals. From this, it is predicted that the lifetime prevalence of depression within epilepsy is up to 55% (Jackson et al., 2005). As with depression, anxiety can be seizure related. Fear is a common indicator of seizures and it can sometimes be difficult to distinguish between these and panic attacks.

Between the psychiatric conditions in children and adolescents with epilepsy, depression and anxiety disorders necessitate additional attention due to it bringing about the risk of reduced quality of life and life-threatening difficulties, an example of this being suicide. Pullianen et al. (2000) states that poorly controlled epilepsy can create increased levels of anxiety and depression. Depression in epilepsy may be catatonically induced with various antiepileptic drugs used to treat the seizure disorder or after surgical treatment of intractable epilepsy. Despite its relatively high prevalence, depression remains unrecognised and untreated, and unfortunately its treatment is based on empirical and uncontrolled data.

Vazquez and Devinsky (2003) suggested that, death by suicide is more common in individuals with epilepsy compared to the general population who do not suffer from it, for example 5% compared to 1.4% (Jackson et al., 2005). Factors associated with increased risk have been reported to include: younger (25–49 years) male patients, co-existing psychopathology including personal difficulties including social or work related problems, personality disorders, prolonged duration of epilepsy, and poorly controlled seizures. Individuals with epilepsy often have access to large quantities of anti-epileptic drugs and 80–90% of suicide attempts are overdoses.

Both hospitals and community based studies of epilepsy have found the occurrence of an inter-ictal anxiety disorder to be between 10–25% and, in the majority, this is a generalised anxiety disorder (Turkington et al., 2004).
Chapter Four

Methodology
Methodology

This chapter will analyse and justify the methodology of the research study. This will include an analysis of why qualitative methodology was used, the ethics involved, an explanation of the sample produce and technique, and finally the method of data analysis.

Qualitative Study

In the case of the research study a qualitative method was used. According to Denzin (2005) qualitative research is an extensive methodological approach that includes a wide range of research techniques. The aim of qualitative research can vary due to the disciplinary background. Wyse (2011) states that qualitative research is used to explore the thoughts, feelings and the lived experiences of individuals with epilepsy. It is also used to increase an understanding of underlying reasons, opinions, and motivations. A qualitative study provides insight into exploring or developing ideas for further potential research. It also uncovers trends of thought and opinions highlighted, and looks in depth into the problem (Bryman, 2008). Qualitative data collection methods vary and can include unstructured or semi-structured techniques (Gill et al., 2008).

Alongside a qualitative study is ontology and epistemology. Ontology and epistemology are two different methods of viewing the research philosophy. Ontology is the philosophical study of the nature of being, becoming, existence or reality as well as the basic categories of being and their relations (Blaikie, 2010). Ontology is a classification of belief that mirrors an interpretation of an individual based on what constitutes a fact. An example being, ontology is linked with a central question of whether social entities need to be perceived as objective or subjective, and it is this that leads a constructive approach using epistemology. Subjectivism also known as interpretivism is the perception that social phenomena is formed through the way in which perceptions and consequent actions of social actors concerned with different existence. For example, Bryman (2012) states that “ontological position which asserts that social phenomena and their meanings are continually being accomplished by social actors”. Therefore, this research is a social process that’s takes a view that we make sense of the world around us.
**Ethics**

Consideration of ethical approval was a significant part of any research study. This is due to protecting the confidentiality and vulnerability of the participants who are involved (Clifford & Valentine, 2003). Within this research study it was the researcher’s responsibility to ensure that all participants were safe guarded, and that no physical and emotional harm was caused to the participants (GMC, 2016).

An ethics application was submitted to the Cardiff Metropolitan Health and Social Care ethics panel. This ethics form contained all the information and highlighted any potential risks to the individuals involved and how to overcome these risks. This involved participant confidentiality and obscurity, not enough participants being involved within the study and the exploration of how the effect of an individual’s diagnosis can bring about emotional effects. Prior to the semi structured interviews being conducted, the participants were provided with information sheets that contained all the information based on what was going to happen during the research (see appendix 2). Participants who agreed to take part and were willing to go further in the study signed an information consent form to confirm this (see appendix 3). Consent in this case is critical as it provides conformation that the participant is willing to participate in the study, and has been provided with all knowledge of all aspects of the study (UNC, 2016). Each participant was provided with the option of withdrawing from the study at any time, and was assured that no explanation was required to the reason why they wish to leave the study. If they had chosen to withdraw from the study, all their personal information would stay confidential under the Data Protection Act (1998).

**Sampling**

The sample used in the study had a confirmed diagnosis of epilepsy and were over the age of 18, and have been diagnosed for over a year. Within the first year of being diagnosed a patient faces multiple stages of treatment and medical investigations to find the correct medication to control the diagnosis (Chadwick, 1988). All the participants that took part in this research study were students from the same university. Cassel and Symon (1994) suggest that it can be difficult to recruit individuals for interviews because they are time consuming for the participants. However, the participants in this study were given the option to
choose their time and date of the interview, meaning they would have felt more in control of the situation and willing to participate. The age range selected was due to no parental consent having to be conducted, creating less complication within the study. Additionally, the chosen topic of this research study can trigger a vast amount of emotions, and have a negative impact on younger participants. This led to nominations of other participants, using a snow ball sampling technique. The snow ball sampling technique is a form of convenience sampling (Bryman, 2012). This approach allows the researcher to create contact with a minority group of people who are related to the research subject, and then use this initial contact to gather and establish other contacts to be involved within the research study. (Bryman 2008). This was the chosen method of sample selection because the sample for this study is not at random. However, it would not be possible to sample select individuals with epilepsy without asking other individuals if they know of any other participants that could have been involved in the study (Becker, 1963, pp. 46). Using this technique, no more than five participants were asked to be involved within the study. As a result of time allocation, this allowed enough available time for the researcher to gain enough valuable information needed on top of transcribing the interviews. Additionally, for this type of study, a small sample is suggested as they ‘reach’ dates or ‘hide’ data.

**Data Collection**

All of the participants were provided with a 60-minute interview space, within the library of either Cardiff Metropolitan LLandaff Campus or Cyncoed Campus. All the interviews were recorded and were of a duration of approximately 30 minutes’ long, depending on how the participant answered the question. Also, time was provided before and after the interview began and finished to create a rapport and allow for any questions to be asked. Rapport is an important feature or characteristic of unconscious human interaction. A rapport can be perspective as being in "sync", or on the same "wavelength" as the person with whom you are interacting with (Evans, 2017)

The location of the room was important factor to take into consideration when conducting the interviews. By using a reserved room at Cardiff Metropolitan University, it entitled a quiet room which allowed the participants to feel
comfortable and allow a private conversation to take place in a public space. The location allowed for a clearer recording of the interview, which in turn made it easier to transcribe, because of the lack of background noise.

The focus of the semi-structured interviews was to gain an understanding of how the participants felt when they were first diagnosed with epilepsy. Furthermore, it allowed for the participants to express how their diagnoses impacted on their physical, emotional and social wellbeing, as well as their daily routines and whether their job aspirations or employment statues had to change. Interview guides are a somewhat more structured list of issues to be addressed or questions to be asked in semi-structured interviews (Brymun, 2008, pp. 695). Interview guides are important as they allow the interview to be conducted in the direction that will allow for the correct answers to be asked, in order to gain the information that is related to the research study. Thus, using open-ended questions allows for the researcher to gain more in-depth information and understanding based on the topic being researched. Interview schedules are significant as they permit the interview to be guided, therefore, resulting in key issues being addressed and topics being answered (Kennedy, 2006). The interview guides (see appendix 4) were created by identifying different themes that were evident from previous research, which is located throughout the literature review. This literature was related to the effects of an epilepsy diagnosis, and how this impacted on an individual’s way of life.

The interviews taken place were semi-structured. “semi structured interviews, also known as standardised interviews include, the administration of an interview schedule by an interviewer” (Bryman, 2008, pp. 193). Using an interview schedule was significant to this research design as it permitted the interview to be guided, therefore, highlighting key issues being addressed and the research topic being answered (Kennedy, 2006). This design was used to allow for the researcher to gain an understanding of the feelings and experiences the participants felt when diagnosed with epilepsy. Furthermore, using a semi-structure approach, allowed for the participants to express how their diagnosis impacted on their physical, emotional and social wellbeing, as well as their daily routines and whether their job aspirations or employment statues had to change.
Prior to the interviews taking place, an interview guide was created. Interview guides allow for a structured list of issues that need to be addressed or questions that need to be asked to obtain the relevant information (Brymun, 2008, pp. 695). Interview guides are important as they allow the interview to be conducted with direction that will allow information to be gathered in relation to the research question. For this research study, the interview guides were created by identifying different themes having already been evident in previous research based around the topic of epilepsy (see Literature Review). Previous literature was related to the effects of an epilepsy diagnoses, and how this impacted on an individual's way of life. Having said this, when making the interview guides, open-ended questions were produced. Using open-ended questions allowed the researcher to gain more in-depth opinions and expressions of experiences based on the topic being researched. Open-ended questions allowed more flexibility in the participants’ answers, and allowed for all relevant aspects of the research study to be explored. By providing the participants with open-ended questions allowed for the participants to be open and free with their given answers, resulting in more in-depth answers, thus, proving the researcher with more subjective information for the research study. Using an semi-structured interview, based around open-ended questions is said to extract information to achieve a holistic understanding of the participant's views in a specific situation (Berry, 1999) and allow the participants to respond freely (Turner et al, 2010).

All the interviews were recorded on three separate devices, which all contained a voice recording application. By recording the interview on three different electronic devices it reduced the risk of data loss due to technical fault. The recorded data was then transcribed onto a computerised password protected Microsoft Word document. Norman (2011) stated that "collecting density and flow rate data in real-time is helping to lower drilling costs by reducing non-productive time and identifying leading indicators to potential operational problems, which contributes to real-time drilling optimisation" (Norman et al, 2011, pp22.)

**Reliability and Validity**

Bryman (2008) states reliability relates to the consistency of a measure of a concept, and validity refers to the issue of whether an indicator that is devised to measure a concept really weighs that concept. Patton (2002) states that validity
and reliability are two factors that need to be considered in any qualitative research. Healy and Perry (2000) declare that reliability and validity are essential criterion for quality in qualitative paradigms, the terms credibility, neutrality or confirm ability, consistency or dependability and applicability or transferability are to be the essential criteria for quality (Lincoln & Guba, 1985).

**Data collection storage and analysis**

After the interviews had been conducted, a thematic analysis was used to make sense of the data provided from the participants. Sgier (2012) states that a thematic analysis is the most common type of qualitative analysis that seeks to identify patterns, commonalities and contrasts within the content of data. A thematic analysis precedes over stages of well-defined steps, these being categories of building, coding and highlighting common trends within the evidence provided (Bryman, 2008). To document this analysis, the interviews were transcribed onto a password protected computer. This allowed the researcher to locate the exact responses given from the participants and the location of key themes were appointed from the natural resource. The content that was part of a theme or of a significant importance was highlighted and set alongside with similar themes and quotes. This resulted in the ability to find a relationship between these themes and compare the differences.

Once all the information was gathered from the thematic analysis, a report was created highlighting the main matters from the given answers, and described why these issues were important. The report also points out any insinuations of practice that could have instigated problems throughout the research.
Chapter Five

Findings and Analysis
Findings and Analysis

The purpose of this study was to gain an insight into the effects of an epilepsy diagnosis on an individual’s lives, and to discover what these effects were and how they have affected their lives. There is minimal literature that identifies individual’s views with regards to their diagnosis, meaning this research project could be useful for increasing peoples understanding on how an epilepsy diagnosis can impact and change a person’s life. Semi-structured interviews that were implemented for each participant helped to receive in-depth answers to collect and gather the correct information. This examination of the qualitative data, generated five key themes from the data that have effects on social well-being, the family, employment, education and physical activity. These themes were then broken down into sub-themes to provide a clear representation of the results for the discussion (Appendix 5). Within the discussion no names were used, as an alternative the participants were addressed as numbers, for example participant 1 (P1).

Social Well-being

The most significant finding from the data gathered was the impact of an individual’s epilepsy diagnosis on the individual’s social well-being. All four participants identified that their social well-being has changed. This suggests that participant’s social lives have altered and created limitations within their social well-being. When asked if it has affected their social life, participant two stated;

“Yes definitely, I went through a period when I was 12 years old and everyone was going out shopping and going to school discos, and I just couldn’t, like I just was too scared to go in case something happened sort of thing… I couldn’t go to discos because the flashing lights.” (P2)

“It has affected my social life slightly. Due to the university life style where you are used to socialising partying, going on socials playing sport… with my friends became something that I was not afraid to do but had to think about more now which meant I couldn’t enjoy it more which also meant I couldn’t socialise with them as much, which also had a negative effect on my self-esteem because I was used to socialising with people then it brought me down a level because I wasn’t able to be that social person I was before”. (P1)
Participant four also commented on the changes within university life stating “.. yes, because like when I go out now drinking etc, I have to watch how much alcohol I drink as it can influence me having a fit, also because in university going out it is the norm...”. (P4)

As a result of the social changes, it is evident that this participant had encountered negative emotions during their experience of epilepsy, leading to poor quality of life. In relation to this Michael (2007) states that social isolation and poor social adaptation can result from perceived stigma or over-dependency caused by parental overprotection. Individuals with epilepsy often fear embarrassment by a seizure, causing reluctance to engage in social interaction, with concomitantly low self-esteem and academic under-achievement.

As discussed, participants find it difficult to accept change in their social well-being environment, it is also evident that the participants do not feel comfortable with the amount of publicity that is placed upon their identity. For example

“I hate it, I really don’t like talking about the diagnosis, it was a very stressful time…. It made me feel like my life was over and I was so limited in everything I had to do… I hated it” (P4).

Participant 2 similar to participant 1, agreed and provided that “it is a very touchy subject. I was scared to think, like what would they say if I was having a seizure…” (P2)

However participant three disagreed with participant two and four, findings suggested that “It doesn’t bother me.. it just hard for people to understand if I was just to describe it to others, like most people don’t understand it because it’s so like abstract to them, so I try to like just lame man terms for them because epilepsy is a big part for people”.(P3)

Noted in the epilepsy foundation (2016) it is apparent that individuals feel nervous with discussing their diagnosis, and fear that if their diagnosis becomes known that they will be treated differently.

As a result of reviewing the data collected it is evident that the process of recovery after participants experience a seizure also has a huge impact on their social well-being, due to them being unable to complete daily task and becoming bedbound.
due to tiredness. An example being, when asked how it affects them participants replied saying:

“ It really affects me a few days, aching I can’t move... and stay in the house for at least a few days...and just rest” (P2)

“Usually after one of the major seizures I am affected for 4-5 days as it drains my body. I usually won’t leave the house much and get as much sleep as possible and recover as fast as possible by not wearing myself down, and going into a normal lifestyle straight away can have further negative effects on my well-being” (P1)

“I feel groggy almost like hungover, it’s more like shock, because I wake up and have no Scooby what’s gone on...” (P3)

“I need around two to three days to overcome them and rest up. After having a fit see it makes me really drained and tired, I also lose a lot of my memory, so I am usually very confused for a while about what day it is and tend to forget a lot of things” (P4).

In comparison to this, John (2006) identifies that after having a seizure individuals are prone to a variety of symptoms including fatigue, severe headache, and body aches. Epileptic seizures can also make people more prone to falls and injuries. Experiencing such side effects, decreases the participant’s quality of life as they are prevented from completing daily tasks and interacting with the wider community.

Effects on The Family
Another theme identified from the data was the impact an epilepsy had on the family. It is apparent from the results that individual’s families were also affected by an epilepsy diagnosis. The diagnosis of epilepsy and individuals daily routines creates many implications for the individual, and in turn has an impact on the family members around them. (Leonard and George, 1999)

“.. yeah it has had a huge effect on my family.” (P1)

“.. very stressful time for me and my family”. (P4)
All the participants within the study commented on how their diagnosis has had an effect on their family. Lechtenberg (1990. P.2) indicates that epilepsy “doesn’t only effect the individual suffering from it but that individual’s family as well”. Similarly, Thompson and Upton (1994, p. 19) also suggests that “individuals with epilepsy do not live in a vacuum and any negative values experienced are likely to effect to all family members”. From the data collected it is evident that the effect on the family is multidimensional.

Participants in this study were very consistent in stating how their diagnosis has emotionally influenced their family around them. Participants felt that it was providing distress and causing upset for the people who care for them. Anderson and Barton (1990) identified higher levels of anxiety within the family members of individuals with epilepsy. Kugoh et al. (1989) suggested that an epilepsy diagnosis increased levels of emotional distress in the both the child and mothers of the individual.

“.. it was very stressful time and they just wanted me to be ok and back to my normal self....my brother was quite scared all of the time…my mum was really upset”. (P4)

“.. yeah my mum was really stressed because obviously if you have it seriously you can eventually die from it”. (P3)

“.. it has a big effect on my family I think personally yeah...” (P2).

In a systematic review carried out by Zhuet al. (1998) findings suggested that adults with epilepsy were seen to have higher levels of family-related difficulties in comparison to control groups. Within the 25 studies included, data indicated a trend towards the negative impact of epilepsy on family functioning, and psychological well-being of all members of the family.

The data collected identified that all participants stated that their family were their main support system through their epilepsy diagnosis, commenting:

“.. I have had huge amount of support given to me by my family...” (P4)

“yeah definitely my parents are spilt up but both supportive” (P2)

“My family have supported me yeah” (P1).
Alongside this the participants linked the support provided from the family to physical changes that occurred and family’s daily routines having to change due to them providing support and stability.

“yeah, my mum is always there, she always takes me to the doctors and always encourages me...” alongside saying “… I couldn’t be left on my own...” “... my brother was quite scared most of the time...”. (P3).

“.. my mother used to be like stay in my room all night because she was scared in case something happened and that had a big effect on my family I think, personally yeah”. (P2).

“my parents would keep constant contact with me, …and travel down from Cornwall to Cardiff when I wasn’t well...” (P1).

From the data gathered this shows that family support and physical changes within the family, is large impact on the individua’s lives. The family support has had a main involvement within the participant’s epilepsy diagnosis.

**Employment**

Employment was another theme identified from the data collected. Previous research shows that once individuals are diagnosed with epilepsy their first fear they all relate to is within the fields of employment and career aspirations, this is due to a significant amount of evidence already being shown on the low employment rates within individuals with epilepsy. All four participants in this research study also confirmed this and were aware that they would be limited within their job applications. Participant three gave an example of this:

“obviously there is limitations in what I can do with my jobs, So I can’t go in the army, can’t work as a police officer... so my job is limited...” . (P3)

Alongside this participant three also went on to say how they had already been prevented from working within a work place.

“.. I had a job as a life guard and they didn’t do their checks correctly, and then they eventually found out I had epilepsy, but I wasn’t hiding it, and then they had to put me on hold from working”. (P3)
Collings, (1992) supports this by producing a survey based on employment amongst individuals with epilepsy in the United Kingdom, showing that 26% of 1700 individuals who were surveyed quoted that epilepsy was the purpose for lack of opportunities and job promotions. From these findings, it highlights that epilepsy is linked with the more than expectancy rates of unemployment, specifically within underemployment. The data collected also highlighted this and shows that participants are aware of job limitations, so have to change their career pathway.

Another point identified by a participant is that due to limitations within the work place, because of their disability, they felt that they are prevented from working within certain areas and at certain levels. Thus, preventing their working hours and earning an income.

“*Epilepsy affected my working pattern, and which stopped me from making money*. (P1)

Baker, et al., (1991) support this by reporting that individuals who have epilepsy are more likely to be employed in unskilled or manual jobs.

Moving on from this participant three stated that due to limitations in the work place, they felt stigmatized stating:

“*Yeah I would say I am stigmatized yeah…*” (P3).

This may indicate that employment settings can create emotional effects on individuals with epilepsy, resulting in the possibility of stigma and lower self-esteem, which has been well documented within the literature review.

Disclosure of epilepsy pre and post employment was a concern for participants and they feared that by declaring their epilepsy disability within a work place would prevent them from getting a job or progressing within their job role. For example

“*no one wants to hire someone with a disability do they..*”. (P4)

“*…in general people wouldn’t want to employ someone with epilepsy..*. (P3)

This negativity has made participants fear their position within employment and also to gain employment. MacIntyre (1976) supports this as shown when he
conducted the most significant studies concerning epilepsy and employment. 89% of the 119 individuals with epilepsy out of a total of 150,000 steel workers surveyed, stated no difficulties while working because of epilepsy. Although, only 37% of the workers disclosed their disability before employment. Cooper (1995) touches upon disclosure identifying that it is one of the main issues regarding individuals with epilepsy looking for employment. This became prominent within the data when one participant stated that they have hidden their diagnosis within their current job role. Participant 4 stated:

“I haven't told the company that I am working for that I have epilepsy as I was very scared that they wouldn't hire me if they knew I had epilepsy as they may be scared if I have a fit in work...like if I told them on my application that I had an epilepsy disability they wouldn't have looked twice at bringing me in for an interview, as they probs thought we don't want someone who fits in the work place..” (P4).

If an individual has epilepsy, within the work place the employer is obliged to undergo an individual health and safety risk assessment to ensure the individual with epilepsy can perform the duties of the required role within the work place safely (TUC, 2015). The Equality Act (2010) (England, Scotland and Wales) and the Disability Discrimination Act (1995) support this statement and states that financial support is available to help fund the reasonable adjustments, which can be provided through the Access to Work Scheme.

Employability was also prevalent in participant’s life style choices as participant one commented:

“my driving license had to be taken off me for a year therefore it has affected my decisions on where I may have a job” (P1).

Driving laws relating to epilepsy range in restrictiveness from restoration of a driving license after 12 months’ seizure freedom to a total ban. Waller (1963) suggests that there is a lack of evidence to driving accident rates of individuals with epilepsy. Taylor et al.,(1996) backs this view stating that the rates are no higher than those individual with medical conditions and the general population. Driving ban has also effected other participants such as;
“I also cannot drive so I tend to not go places which is hard to get to, so that has had a knock on affect with my university degree, for example I miss a lot of lectures due to not being able to get to university, as public transport isn’t reliable and also costs a lot of money if I use it daily…” (P4)

“the big thing that really nags me is that fact that I can’t drive” (P3)

In relation to this issue not all participants were effect in particular participant two;

“my medication controls it really well, so my life before it was like I wasn’t able to drive and now it just no different as I can drive…” (P2).

Education

As previously mentioned, in regards to individuals with epilepsy facing difficulties with employment, it was also evident from the data collected that all four participant’s education was also affected by their epilepsy diagnosis. All four participants commented that their educational life had to be altered due the side effects of epilepsy, these being tiredness and attending hospital appointments.

“I was missing a lot of school, because like I was back and forth to the hospital”. (P2)

“my educational life has been altered… I was not able to sit exams and had to get further essays that were due to be in after the year was finished, therefore my work went into the summer, which also affected my working pattern”. (P1)

Furthermore participant 4 said:

“yes totally like now I have been diagnosed and have this blurry vision a lot, it has led to a stressful period of time, because I have been having a lot of tests done, in the hospital… so this has stopped me from attending uni “. (P4)

In support of this fisher (2005) identified that individuals with epilepsy reported within a survey that they receive less education, and were less likely to attend school. From the data collected regarding attendance within school and university, it is evident that from this the participant’s educational life has been reduced and attendance levels in school have been low. Most participants commented on the fact they were unable to attend school due to tiredness from
their medication and didn’t feel confident going to school with an epilepsy diagnosis. For example

“..from my medication I suffer from tiredness, this has affected my every day to day life especially playing sports and attending university..” (P1)

“now I’m on new medication it really makes me tired, so I sleep an awful lot”. (P2)

In line with this Bruno et al (2007) suggests that Seizures have a significant impact on school attendance, and as a result may increase the academic difficulties faced by children with epilepsy.

Therefore, from the data collected it shows that the participants are disadvantaged, as they miss a large proportion of their school and university lessons. This can cause a back log of work to catch up with therefore adding additional pressure resulting in increased stress levels. This has already been described earlier in the research indicating the effects of stress on patients with epilepsy.

Attendance at school can also be sighted with regards to individuals being scared to leave the family home, or be within an environment with people who are unaware of epilepsy. This makes them scared to share their diagnosis. From the data collected all participants made recollection, in regards to having fear of attending school or leaving the home.

“.. I was a bit nervous to go to school because I didn’t know how people would react if something happened in lessons and it was like scary for me. So I missed school”(P2).

“Its another added pressure.. if people know then its out there and not a big deal, where as if it comes out then people make more of a fuss which could stress me out more”. (P1)

From this the data showed that all participants therefore made their peers aware of their diagnosis, in case a medication situation arose. Participant three commented; “.. I have to tell all my friends to be aware of what’s going on and always wear a medical necklace..”. (P3).
“.. I don’t like talking about it… obviously to my friends I had to tell them and talk about it as they seen me upset and throughout the stressful stages…” (P4),

“.. if anything it’s good to tell people, because people need to know if I ever have a seizure or told them I wasn’t feeling well then they would know how to handle it and also not panic..” (P1).

Epilepsy action (2017) supports this suggesting that individuals may want to hide their epilepsy, but this can be dangerous. If an individual has a seizure then they ought to make sure others are prepared and they know what actions to undergo to ensure they access help and keep the individual safe.

Although all four participants identified from the data collected that they faced difficulties within education, they also all stated that they were provided with support within the school, university they attend, which helps them overcome these difficulties. Participant one commented:

“my personal tutor helped me a lot last year, with getting further extensions as it was a very busy period for me when I got diagnosed as the second term was building up towards exams and important essays.. they helped me as much as they could” (P1).

“university have supported me too, they have given me this disability allowance which has paid for extra help with my uni work and has given me a tutor who then puts into place different work if I cannot complete the work they set, so for example because I keep getting blurry vision and I am unable to sit exams so my tutor puts into place essays instead”. (P3)

This shows that the individuals rights are being respected and their quality of life is being promoted by principles being put into place so they are not at a disadvantage. As a result of this participant one stated:

“..in the long run it was beneficial for me and I ended up getting the grades I was capable of getting”. (P1).

Also, when participant three was asked if the university had supported them with their epilepsy they replied:
“yes they have been really good with it, they have given me disability help, so yeah I would say they have helped”. (P3).

It is apparent from the results that individuals face difficulties within education due to the epilepsy diagnosis, and the demand of hospital appointments. The evidence form the data collected shows it is apparent that these struggles are supported. On the other hand, one participant commented that yes, they were provided with support, but it wasn’t made known to them until they were told by a tutor.

“before the care was provided I didn’t have a clue it existed, my tutor was the one who told me to apply once we found out about my diagnosis”. (P4)

Alongside this participant, one noted that the support provided to them at the start was poor, commenting:

“…at first I felt like I wasn’t provided with the best support purely because I felt they didn’t take it seriously…”.(P1).

During the interview, the three participants also made recollection to how they were not made aware in relation to the disability allowance in order to provide extra support, but once prompted and applied this was addressed.

**Physical Activity**

The final theme identified from the data was the impact epilepsy has on sporting activity. Data collected showed three out of four participants identified that they suffer difficulties within sporting activities. When asked if their medication affects them physically or mentally, three participants gave examples of how their medication affected their sporting activity, for example

“.. also affected how I went about my day to day life especially within my playing sports, as I was in the rugby league squad for Cardiff Metropolitan University, and I had to stop playing because of the effects of my medication, giving me side effects that affected my performance and also my health”. (P1)

“my rugby ability has definitely changed a lot, so I have to again make sure that my coaches are aware, so sometimes when the flickering lights from the trees can alter my judgement and can be quiet dangerous” (P3)
“I had to leave the university cheer leading team, because my health was a concern, and I felt very scared to perform stunts while being tired from my medication, this was a difficult time for me as I was a very active person, and even stopped going to the gym, as I kept getting blurry eye vision, when on the running machine and lifting weights, so again this was a concern for me so I stopped going has hated the feeling..” (P4).

Arida et al, (2008) relates to this suggesting that individuals with epilepsy have previously been discouraged from participation in physical activity due to having a fear of inducing seizures or increasing seizure frequency. Despite a change in medical recommendations toward encouraging rather than restricting participation, the stigma remains and individuals with epilepsy continue to be less active compared to the general population.
Chapter Six

Conclusion
Conclusion

The aim of this study was to explore the effects of an epilepsy diagnosis and see how it effects an individual’s life and their life decision’s. Overall, the results were similar with previous literature that explored the effects of an epilepsy diagnosis within patients with epilepsy.

The most significant discovery was that the participant's social well-being was highly affected by their epilepsy diagnosis. The findings were significant to previous literature showing that epilepsy influences culture, identity and well-being (Baker, 2002). Information gained regarding the impact on social well-being also highlighted that these influenced individuals self-imagine. This is important to the reader because it explores why individuals social-wellbeing is impacted and highlights the need for coping strategies to help support the participant's needs and improve their equality.

Another major finding from the study was that participant's families were hugely affected by the individual's epilepsy diagnosis. This was supported by previous literature by Leonard and George, (1999) suggesting that a diagnosis of epilepsy and daily living with the condition have implications for the individual, but it also has consequences for all members of the family unit. Although the data gathered from the participants identifies that their family found an epilepsy diagnosis difficult, all participants adopted a support system from their family members. Rodenburg (2005) supports this suggesting parental support reflects the degree to which parents provide a warm, safe, responsive emotions to individuals with epilepsy.

A significant amount of data collected also highlighted the impact of which an epilepsy diagnosis had on the participant’s employment, in which one participant identified not declaring it. This therefore highlighted stigma, prejudice and discrimination.

An unpredicted finding arises within the data, this being the impact that epilepsy has on sporting activity. Participants identified that due to the change within their health status, this caused complications within physical activity. In line with this Ricardo & Arida et al, (2008) has identified that an epilepsy diagnosis creates fear and prevention within sporting activity, but he also suggests that most sports are
safe for epileptics to participate in, with regarding special attention to adequate seizure control, close monitoring of medications, and preparation of family, coaches, or trainers.

**Strengths and Limitations**

Primarily, simplification of the data cannot be useful as the participants were all from the same university applying that this could impact on the responses they gave and effect the results of the study. The outcomes could be comprehensive if the sample was from a wider range of areas across the United Kingdom and involved individuals who were not in education and are within a working environment. Though there were only four participants who took part in the study who were over the age of 18, to avoid major differences, and all participants were students at the same university, for future research the younger generation of individuals should be used, or the research question should be directed to a bigger population of society.

The data cannot be comprehensive since the sample size of the research study was too small, with a total number of 4 participants used. Because of this, the data collected ought to be observed with caution due to the small number of participants to create reliable and generalised results.

An asset of this study is the influence of research it delivers. There is little literature on the individuals first hand views based on their epilepsy diagnosis, therefore the data gained from this study can be used as a recommendation for forthcoming research.

Researchers can develop and expand the results further to perceive how an epilepsy diagnosis can affect individuals and the main effects of this, and explore different age ranges to see if the effects are different. Via looking at different age ranges distinctly, researchers would be able to identify if the age affects individual’s perception of an epilepsy diagnosis and life changes. It will also identify what effects does it have on the participant, and whether the age of the participant determines if an epilepsy diagnosis may have a different impact on their lives. For example, does it create a bigger impact on a child’s life style choices and decisions, or more complications if diagnosed when older.
Recommendations

Suggestions for future research include data as to how individual’s families are affected by their epilepsy diagnosis. Information gathered from this study shows that families where both emotionally and physically and effected, but a first-hand view of their opinion is needed to be obtained.

As cited in the strengths of the study, building on the results already gained from this research and expanding them to age ranges will be useful for future research. This is because it will allow an understanding on how age affects individuals and family’s perception of their health and wellbeing through the stages of an epilepsy diagnosis and if this will allow a differing of the stigma associated. For example, if an epilepsy diagnosis is adhered during a young age then can this be treated straightaway and controlled, therefore resulting in having no affect within later life.

Reflective learning

Gibbs’ reflective cycle was used to analyse and reflect on the experience of conducting this research study.

Throughout this research study I have been challenged to the best of my ability, alongside this I have experienced mixed emotions of happiness and frustration. The research study has been a huge emotional journey and have provided me with a huge sense of pride and achievement. It has demonstrated to be a sensitive study, due to being a topic that has made a huge impact on both my own life and my families, and it was due to this that this particular choice of topic was chosen. Throughout process of gather research I gained an understanding into appreciating the time that was needed to analyse the data correctly, before incorporating it into the research study. Locations of study were a major fact to take into consideration when completing this study, this was due to avoiding locations which will increase my levels of procrastination.

Daily check lists were created in order to maintain my focus levels and to avoid losing relevant time on irrelevant information, and not focusing on one part of the study in too much depth. By doing this I was able to allocate my focus equally on all parts of the study, and alongside this ensuring that time was provided to myself away from the study to ensure that a healthy balance of studying and family life
was completed. Even though I found it very challenging to unwind and spend time with friends and family due to stress levels being high.

The results of the study have shown me that there is a wide range of literature based on the subject of epilepsy but little knowledge on the individuals first hand views and understanding of being diagnosed, and the impact it has on them. From this I believe that although the data collected from this study is minimal due to only interviewing 4 participants, I believe it can be used as a recommendation for forthcoming research. Alongside this future research based on the younger generation of individuals should be conducted, or the research question should be asked to a greater population of society and with people from different areas

When conducting the semi-structured interviews for my data collection, I found this to be a very overwhelming experience. This challenged my own views and understandings of epilepsy and gave me an insight into how it has also had a big impact on other people’s lives and not just my own. I have found from the data collected that individual’s life and life decisions have had a huge impact due to their epilepsy diagnosis. More research needs to be conducted to gain a greater understanding on ways to overcome these impacts and coping strategies required to be implemented within society.


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Appendices
Appendix 1

Wednesday, 21 December 2016

BSc (Hons) Health & Social Care
Cardiff School of Health Sciences

Dear Applicant

Re: Application for Ethical Approval: An investigation of the effects of an epilepsy diagnosis on an individual’s life and life decisions

Project Reference Number: [Redacted]

Your ethics application, as shown above, was considered by the Applied Community Sciences Ethics Panel on 21/12/2016.

I am pleased to inform you that your application for ethical approval was APPROVED, subject to the conditions listed below – please read carefully.

Special Conditions of Approval

1. Amend the start date for data collection

Please confirm by email to acs@chescs.cardiff.ac.uk that you understand the "special conditions of approval" and that where changes to the information sheet, consent form and/or procedures are deemed necessary, these have been carried out as requested. If you are a student – your supervisor must do this.

Standard Conditions of Approval

1. Your Ethics Application has been given a Project Reference number as above. This MUST be quoted on all documentation relating to the project (E.g. consent forms, information sheets), together with the full project title.

2. All documents must also have the approved University Logo and the Version number in addition to the reference and project title as above

3. A full Risk Assessment must be undertaken for this proposal, as appropriate, and be made available to the Committee if requested.

4. Any changes in connection to the proposal as approved, must be referred to the Panel/Committee for consideration without delay quoting your Project Reference Number. Changes to the proposed project may have ethical implications so must be approved.

5. Any untoward incident which occurs in connection with this proposal must be reported back to the Panel without delay.

6. If your project involves the use of samples of human origin, your approval is given on the condition that you or your supervisor notify the School of your intention to work with such material by completing Part One of the form entitled “Notification of Intention to Work with Human Relevant Material or Human Bodily Material” which must be obtained from the PO (Sean Duggan), BEFORE any activity on this project is undertaken.
This approval expires on **21/12/2017**. Please set a reminder on your Outlook calendar or equivalent if you need to continue beyond this approval date. It is your responsibility to reapply / request extension if necessary.

Yours sincerely

[Signature]

Professor George Karani  
Chair of Applied Community Sciences & Protection Ethics Panel  
Cardiff School of Health Sciences  

Tel : 029 20416855  
E-mail : gkarani@cardiffmet.ac.uk

Cc: Stevens-Woods, Kirsten  

PLEASE RETAIN THIS LETTER FOR REFERENCE
Title of project: an investigation of the effects of an epilepsy diagnosis on an individual’s life and life decisions.

Project Reference Number: xxxxx

The aim of the project is to explore how an epilepsy diagnosis has an effect on an individual’s life. As a participant, you will be interviewed to find out how you felt after being diagnosed and whether your daily life changed and how this impacted you. This will help to answer the project question and be able to compare different individual’s experience of being diagnosed with epilepsy. The interviews will take up to a maximum of an hour and will take place in Cardiff Metropolitan university, Llandaff Campus.

- This is a formal innovation for you to join the study, and to inform you of what this will involve. The study is being carried out by a year 3 health and social care student from Cardiff Metropolitan University names xxxxx.
- If you want to improve your awareness and knowledge of what will be required by yourself within the study and want to know more about the project, please contact xxxxx or Kirsten Stevens Wood on the contact details shown on the bottom of this sheet.

Your Participation in the Research Project

Why you have been asked?

You are being asked to take part in this study because you are an individual who has been diagnosed within the last 3 years with epilepsy.

What happens if you change your mind?

If at any time during the project you want to withdraw yourself from the study, you are free to do so. If this is the case then please contact myself xxxxx on the contact information given at the bottom of the letter to inform about your withdrawal, and preventing miscommunication.

Are there any risks by taking part in the study?

By taking part in the study I do not believe that there will be any significant risks during the project. The questions being asked within the interview are not of an
invasive nature and should not make you feel uncomfortable at anytime. If however during the project you do feel uncomfortable, please inform me and we can stop the interview, or you can just state which questions you don't feel confident in answering and we can skip them. You can also withdraw from the interview at any point.

Confidentiality

All the information gathered from you within the study is strictly confidential, and no personal information you provide will be accessible to anyone another than myself or my supervisor. All the date collected for the study will be stored in line with protection act (1998), and throughout the study you will be referred to as a participant.

**Contact details**

xxxx-xxxxxcardiffmet.ac.uk  Kirsten Stevens Wood-

kstevens-wood@cardiffmet.ac.uk
Participant consent form

Participant name:

Title of Project: an investigation of the effects of an epilepsy diagnosis on an individual’s life and life decisions

Project Reference Number: __________________________
Name of Researcher: __________________________ student number: __________________________

Participant to complete this section: please initial each box.

I confirm that I have read and understand the information sheet for the above study. I have had the opportunity to consider the information, ask questions and have had these answered. __________

I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason. __________

I agree to take part in the above study. __________

I agree to the interview being audio recorded __________

I agree to the use of anonymised quotes in publications __________

____________________________________  __________________________
Signature of Participant  Date

____________________________________  __________________________
Name of person taking consent  Date

____________________________________  __________________________
Signature of person taking consent

When completed, 1 copy for participant & 1 copy for researcher site file
1. When were you diagnosed?

2. How did you find out that you had epilepsy?

3. How did you feel when you were told you had epilepsy?

4. Is your life different now you have been diagnosed?

5. Since being diagnosed has your working or educational life had to be altered? If yes how?

6. After having a seizure does it affect you for a few days after or can you carry on with normal day to day life straight after it?

7. Does your prescribed medication physically/mentally affect you?

8. Has anyone supported you with your illness?

9. Where have you chosen your support?

10. Did you tell people that you have epilepsy?

11. Has epilepsy ever had an effect on your social life?

12. Has anyone else in your family got epilepsy and did you ever think would be diagnosed with it?

13. Has your diagnosis had an effect on your family?

14. How do you feel when people ask you about your diagnosis?

15. Anything you would like to add?
Appendix 5

Hierarchy Diagram of themes