

CHAPTER FOUR: THESIS

**NARRATIVES OF LIVING WITH EPILEPSY DIAGNOSED IN
ADULTHOOD**

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JUNE 2011

STUDENT NUMBER: 08190847

**A THESIS SUBMITTED IN PARTIAL FULFILMENT OF THE DOCTORATE
IN CLINICAL PSYCHOLOGY AT THE UNIVERSITY OF
HERTFORDSHIRE**

WORD COUNT: 29,908

Acknowledgments

Melanie (Research participant), "I definitely think it needs to be put out there a bit more and people shouldn't be scared of it, but it is being scared of the unknown, isn't it?"

This sentiment of there being something that others perhaps do not understand, a 'mysticism' that makes some people fearful was one of my calls to this research. The fact that onset is often sudden and, when it happens in adulthood leads people on a different journey to the one they had anticipated, intrigued me. I hope this research effects intrigue in others and helps to build understanding.

I would like to thank the participants for their generosity in sharing their experiences. I would also like to thank my supervisors, Wendy Solomons and Sally Kendall and also Sue Usiskin who acted as an expert consultant, for offering their time and sharing of their expertise. I would also like to thank my fellow trainees for their support and encouragement. Finally, but most importantly, I wish to thank my family and friends for their support and belief in me, and Joshua for his love, smiles and reminders that I could do it, one-step at a time. Thank you.

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ABSTRACT

Background and aims: The individual's experience of living with epilepsy is often neglected with the dominant focus being upon seizure control. However, the experience of living with epilepsy is more than the seizures. Epilepsy is an illness that is understood in many different ways and the narratives the person draws from will impact their own understanding, experience and management of the condition. Based upon this gap in the literature this study sought to hear the narratives of people diagnosed with epilepsy in adulthood as told to an outsider with the hope of developing understanding, informing clinical practice and improving support for people diagnosed with epilepsy in adulthood.

Methodology: A qualitative approach was chosen for this project. A purposive sample of eight individuals diagnosed with epilepsy in adulthood was recruited. Individual interviews were conducted, audio-recorded and transcribed. Narrative analysis was used to analyse the transcripts with a focus upon both what was spoken about and how it was told.

Analysis and findings: Each participant is introduced individually, presenting a 'global impression' of their narrative. This is followed by a consideration of the similarities and differences across all participants under the shared plots of stories of: onset; changes and challenges; and meanings of epilepsy. Within the shared plot of stories of onset are the storylines of 'affirmation' of self; 'continuation' of self; biographical disruption and searching for a cause. Within the changes and challenges shared plot there are storylines of: dependency; emotional expression; '*I try to think positively*' and '*It's like talking about someone else.*' Within the final shared plot of meanings of epilepsy there are storylines of: something 'normal'; something 'all a bit scary'; something '*people used to get locked up for*'; a 'hidden illness' and '*it's not to be spoken about.*' The narratives show that having epilepsy is a journey that has different effects on people at different times of their lives and in different contexts. The findings are discussed in relation to clinical implications; strengths and limitations of the methodology and directions for future research.

CHAPTER 1: LITERATURE REVIEW AND INTRODUCTION

This chapter begins with the researcher's position, to help the reader situate the study, followed by a summary of the literature search. The chapter then introduces epilepsy, the aetiology and epidemiology and how epilepsy is currently understood within the Western health care system. These can be viewed as the 'medical narratives' which currently guide health care and provide a context to the experience of living with epilepsy. The chapter then considers broader cultural and historical narratives of epilepsy. Further narratives are explored through a review of psychological and sociological literature on the impact of epilepsy on people and their 'adjustment' to this new experience. This is followed by a critical review of the qualitative literature of the experience of living with epilepsy in adulthood. Finally the chapter discusses the clinical relevance and aims of this research.

1.1 My position as a researcher

Goffman (1974) noted that every tale is told from a particular vantage point. To understand the author's vantage point, and fitting with the epistemological position that all knowledge is situated, I wish to begin by stating my position and where my interest in this field began. Whilst working as a trainee clinical psychologist in an adult NHS community psychology team I received a referral for the treatment of anxiety of a 30-year-old white British woman recently diagnosed with epilepsy. In our initial meeting, she spoke of her struggle to understand the changes to her life and identity as someone with epilepsy. Her 'story' incorporated events, their meaning to her, and her uncertainty as to who she now was. I was struck both by the range of responses to her struggle from professionals, significant others and strangers, and the effect of these upon her own experience and narrative construction.

On a personal level, intensified by shared gender, age and ethnicity, this case led me to think about my own identity, how centrally I narrate myself as healthy and how such a change would impact upon the narratives I told and others told of me. It also led me to question the impact of local and societal narratives upon an individual's narratives. Societal or cultural narratives are collective narratives within a society or culture that may become the dominant narrative if most prominent at that time and

context. Within this research personal narratives, which will be used interchangeably with the term story, are defined as “*sequential and meaningful*” re-presentations of experience, “*reconstituting it as well as expressing it*” (Squire, 2008, p. 42). People draw from cultural and societal narratives (Rosenwald & Ochberg, 1992) to construct their own narrative – both to make sense of their experience, and to tell the story to others.

This woman’s story sparked my interest in epilepsy and narrative theory and methodology. I have chosen to use narrative analysis, guided by the position that we have a natural propensity to talk in stories, which are shaped by cultural resources and contexts (Frank, 1995; McLeod, 1997). It is through narratives that we actively construct our identity (Gergen & Gergen, 1997; Polkinghorne, 1991). Stories are socially and culturally communicated and performed through generations. This is somewhat striking in the field of epilepsy where the dominant narratives are often stigmatising potentially leading an individual to develop additional meanings of living with epilepsy.

The lenses through which I will narrate this research are postmodernism and social constructionism. This epistemology positions stories as being co-constructed in interaction and open to multiple interpretations. This position, and its suitability to the research question, will be further explored within my methodology section.

1.2 Literature Search

A systematic literature search over a period of 18 months guided this chapter in order to ensure thorough coverage and to reduce the potential for bias. The literature search consisted of several stages that will be summarised here; the full details of the literature search are highlighted in Appendix A. The search began with a preliminary stage using a limited set of key terms (e.g. epilepsy; narratives; biographical disruption) in the databases Psych Info, Annual Review and Google Scholar. References from generated articles were followed up and relevant key words recorded. At this stage researchers in the field were contacted from which further references were sourced. From this a list of key search terms was developed, in addition

inclusion and exclusion criteria were set for the search. One of the main exclusion criteria, which narrowed the generated articles significantly, was a focus upon ‘lived experience’ and psychosocial impacts rather than medical or neurological impacts of epilepsy. The key search terms were used, applying Boolean and truncation options, within several search engines including Web of Science, Pubmed and CINAHL. In addition World Wide Web searches of epilepsy charities such as the National Society for Epilepsy and government advisory sites such as Department of Health were conducted.

1.3 Epilepsy

1.3.1 Epidemiology and Aetiology

Epilepsy is the most common chronic neurological disorder in the UK with a prevalence rate of one case per 131 people (Joint Epilepsy Council [JEC], 2005). It is defined as “*recurrent epileptic seizures of primary cerebral origin*” (Stokes, Shaw, Juarez-Garcia, Camosso-Stefinovic, & Baker, 2004). It is estimated that approximately 50 million people around the world have epilepsy (Jacoby, 2002) with a higher incidence rate in males (Banerjee & Hauser, 2008). In contrast to the general population, mortality rates due to epileptic activity and injury are at the highest for those under the age of 40 (Sander & Sillanpää, 1997); with 1000 people dying (across the age range) in the UK each year due to epilepsy related causes (Hanna, 2002). Epilepsy is a chronic illness that is characterized by seizures. These seizures can take different forms, from absences where a person may lose conscious awareness for a few seconds and may be described as looking ‘vacant’, to someone losing control of all bodily functions, with muscle activity of limbs jerking which is out of the person’s control. It is the latter seizure type that has been associated with the ‘anomic fear’ (Bagley, 1972) of epilepsy and some of the stigmatising narratives discussed later in this chapter.

Within the Western medical diagnostic system, to receive a diagnosis of epilepsy the person must have experienced at least two seizures caused by excess electrical activity

in the brain for which there is no immediately identifiable cause (Stokes, et al., 2004). Epilepsy, or ‘epilepsies’ which denotes how it is a collection of syndromes with a common underlying neurological feature (Stokes *et al.*, 2004; JEC, 2005), has been classified for diagnosis and treatment by aetiology, type of seizures or the location of activity (Engel, Birbeck, Gallo Diop, Jain, & Palmieri, 2005). The International League Against Epilepsy (ILEA, 1981) specify three types of seizures; generalised, partial and unclassifiable. However, this classification is disputed and is undergoing review following medical advancement and understanding (Berg et al., 2010). In the majority of newly diagnosed adult cases, there is no identifiable cause (Porter, 1993), adding to the uncertainty of the condition. For this reason the diagnostic process in itself is a complex and lengthy process for many people.

1.3.2 Treatment and Management

The main treatment for epilepsy is anti-epileptic drugs (AEDs) which aim to achieve seizure control. However, this is often alongside significant side effects (Baker, Jacoby, Buck, Stalgis, & Monnet, 1997). It is estimated that 52% of people with epilepsy in the UK are seizure free or in remission (Moran, 2004). For epilepsy, remission is classified as being seizure free for five years on or off treatment (Stokes, et al., 2004). This means that a person in remission still lives with the uncertainty of whether they may have a seizure in the future. In addition to the legislative limitations placed upon people with epilepsy, for example; not being able to engage in certain careers such as working within the armed forces, and living in a society in which epilepsy is commonly misunderstood.

Psychological interventions in the form of Cognitive Behavioural Therapy (CBT), relaxation or biofeedback are recommended, by the NICE Epilepsy guidelines (2004), in conjunction with anti-epileptic medication where either the individual or the health professional deems seizure control to be inadequate. The focus of these interventions is stated to be control of seizures, followed by a statement that psychological interventions “*may be associated with an improved quality of life for some individuals*” (p.27).

The focus of the NICE guidelines (2004) is primarily upon seizure control, firmly placing epilepsy within a medical model. This model would predict that seizure control would in itself impact upon quality of life and general wellbeing. However, it has been shown that control of seizure frequency or severity is not solely associated with quality of life. Bishop & Allen (2003, p. 227) stated that “*the impact and consequences of epilepsy cannot always be understood as resulting directly or logically from the occurrence of seizures.*” Many factors can impact upon the experience of living with epilepsy, from the daily impact of physical and cognitive side effects of seizures to the consequences of life choices made as a result of the condition. The sole focus upon seizure control ignores the emotional and psychosocial impacts of living with epilepsy and the role of societal and cultural narratives which can affect individual experience.

1.4 Cultural and societal narratives of epilepsy

The current dominant narratives of causation and treatment of epilepsy within Western countries are predominantly medical, as described in the preceding section. However, there are many narratives about epilepsy and the narratives the individual draws from will affect their own narrative and management of the condition (Smith & Sparks, 2002). This section will consider some of the dominant cultural and societal narratives of epilepsy.

Epilepsy has been referred to across the years as the ‘sacred disease’, a sign of genius or of spirit possession (Tempkin, 1971). Andermann (2000, p.170), stated that across cultures and settings “*traditional beliefs about epilepsy can be grouped into four themes: epilepsy as a punishment or sin, epilepsy as bewitchment or possession, epilepsy as contagious disease and epilepsy as a disease of the brain.*” With increased biomedical knowledge, Western understanding has moved towards the current biological basis of aetiology. However, this is relatively recent and up until the 1950’s people with epilepsy were institutionalised, being seen as ‘deviants’ or mentally unstable, and were legally prohibited from marrying in the UK until the 1970’s. During this period epilepsy was often included within educational texts under the sections of mental disorders or criminal behaviour (Schneider & Conrad, 1980) and in

some countries including the United States of America there were eugenic sterilisation policies (Dell, 1986). Despite advancement in medical understanding and treatment, these narratives are still present. Such narratives can impact upon the individual's sense of self worth through repeated discreditable evaluations of the self (Charmaz, 1983) which can sometimes lead to strategies of concealment for fear of the reactions of others (Goffman, 1963; Scambler & Hopkins, 1986; Schneider & Conrad, 1981). This is particularly prominent in relation to employment (Jacoby, 1994) and marriage, where individuals may conceal their diagnosis to spouses or are known within their communities as not eligible to marry due to their diagnosis (Santosh, Kumar, Sarma, & Radhakrishnan, 2007; Scambler & Hopkins, 1986; Tran, Odermatt, & Singphuangphet, 2007).

Narratives of epilepsy vary within and between cultures and religions. The dominant understandings impact upon the narratives of epilepsy and the treatment of the person. These narratives are guided by social context and societal beliefs of the causes of epilepsy. In addition to whether epilepsy is located within the individual or within a wider context such as the family or community in which they live. In China to have epilepsy is said to bring 'moral shame' to the family representative of the collectivist society (Kleinman et al., 1995). In Vietnam explanations are focused around notions of bodily imbalance (Jacoby et al., 2008) whereas in Africa it is predominantly around spirit possession (Snow & Lisk, 2010). Snow & Lisk (2010) stated that in Sierra Leone sudden onset in adulthood is related to possession by the devil. They stated that 80% of people with epilepsy in developing countries will seek healer treatments, which may vary from herbal remedies to sacrificing arms. A study of the South Asian community in Bradford, UK, showed how the narratives of epilepsy being contagious or the result of possession by spiritual beings (*jinn*s) are still strongly held, particularly by elders or those who were born or grew up in South Asia (Small, Ismail, Rhodes, & Wright, 2005) and that often treatment is sought from religious healers alongside NHS treatment (Ismail, Wright, & Rhodes, 2005).

A dominant societal and cultural narrative of epilepsy, and one which has been researched and written about extensively, is its association with stigma and being stigmatised. Trostle (1997, p. 2187) stated, "*to have epilepsy is to open oneself to the*

full force of past and contemporary social prejudice and misunderstanding” As stated earlier, the stigma associated with epilepsy has been attributed to the ‘anomic fear’ of people seeing someone in a state of loss of control (Bagley, 1972). Goffman (1963) defined stigma as an “*undesired differentness*” stating three categories of stigma, one of which was “*abominations of the body*”, which has been related to the presentation of epilepsy during certain seizures. Goffman (1963) spoke of having a “*contaminated*” social identity, which, even if concealed, was still present as a “*spoilt identity*.” Schneider & Conrad (1981) spoke of a “*moral weight*” which individuals carry whilst Scambler (1989) spoke of the “*epileptic identity*” that overrides the person’s past identity and becomes the main focus of who they are. Scambler & Hopkins (1986) following a community study in the UK proposed the ‘hidden distress’ model which spoke of the difference between felt and enacted stigma, the former having been found to be more apparent in Western countries (Jacoby, 1994). The premise underlying this model, and a central feature of epilepsy, is its ‘hidden’ nature in that most of the time a person with epilepsy can ‘pass’ as ‘normal’ aligning self with preferred or more ‘acceptable’ identities. This highlights the powerful nature of dominant narratives in shaping meanings and management of experience. It is such perceptions which can lead people to conceal their epilepsy, develop more socially acceptable or ‘tellable’ narratives (Smith & Sparks, 2008) or use less stigmatising words for it, such as ‘*dizzy spell*’ (Trostle, 1997) or ‘*bayilma*’ fainting (Good & Del Vecchio Good, 1994) for fear of others’ reactions, so perpetuating a self-fulfilling prophecy that there is something to be hidden or undesirable about the illness. If negative views are held within families parents may inadvertently become ‘*stigma coaches*’ perpetuating stigmatising narratives (Schneider & Conrad, 1980). The stigma is also enacted at a societal level through legislation. For example, prohibiting individuals with epilepsy driving for up to a year, a timeframe which varies by country questioning its validity (Fernandes, Snape, Beran, & Jacoby, 2011), and also restricting access to certain careers, (Jacoby, 2002). The current media portrayal of epilepsy also often perpetuates the fear of epilepsy and the narrative of individuals’ deviant behaviour (Baxendale, 2007).

Epilepsy is an illness that is understood in many different ways within and between culture, societies and contexts. All these narratives impact upon the person's understanding of their illness, how they live with it and the narrative they tell (Smith & Sparks, 2008). Within a social interactionist framework (Blumer, 1969), epilepsy could be seen to be experienced both individually, in the changing relation to one's body and self, but also socially in how a person is seen and how this affects their experience, understanding and the individual narratives. This highlights the importance of the chosen research methodology, narrative analysis, which focuses both upon the immediate and wider context in which the narrative is constructed to develop understanding of the experience of living with epilepsy.

1.5 Western psychological narratives

The impact of living with epilepsy needs to be considered at the physical, psychological, biological and societal levels (Hermann & Jacoby, 2009). Studies have found increased clinical levels of anxiety (Swinkels, Kuyk, De Graaf, Van Dyck, & Spinhoven, 2001) and depression in people with epilepsy (Gaitatzis, Trimble, & Sander, 2004; Gilliam & Kanner, 2002). These co-morbidities have been associated with the inherent uncertainty of epilepsy, which was stated to be the greatest concern in a study of 1023 people with epilepsy (Fisher et al., 2000). The uncontrollability of seizures, often despite controls the person may put in place, such as reducing stress levels, can lead to learning that responses and outcomes are non-contingent and has been described as a 'blueprint' for the development of learnt helplessness (DeVellis, DeVellis, & Wallston, 1980); a state which is associated to depression (Seligman, 1975). However, studies have suggested a biological link between epileptic activity and the development of depression (Hesdorffer & Lee, 2009). A complicating factor in this debate is that many AED's can induce depression (Mula, Sander, & Trimble, 2006). In addition to the potential predisposition to developing depression there is also the vulnerability factor of living with a disorder that is stigmatised and often misunderstood. This may in itself impact negatively upon the way people with epilepsy view themselves, their world and future which Beck (1976) defined as the cognitive triad and theorised was central to the development of depression.

1.5.1 Psychosocial

The onset and consequences of epilepsy can mean making significant changes to one's daily life. When receiving a diagnosis in the UK individuals will be advised of certain activities they can no longer do alone or at all. For example, it is prohibited to drive for up to a year after a seizure (Beghi & Sander, 2005). This in itself can have a significant impact upon an individual's independence and ability to engage in day-to-day life. For those living in remote areas or who rely on a vehicle for work, this can have serious consequences, and has been reported to be one of the main difficulties of living with recurrent seizures (Martin, Vogtle, Gilliam, & Faught, 2005).

The diagnosis of epilepsy is not just experienced by the individual but also those with whom they have close relationships. Onset in adulthood can lead to changes in the dynamics of a relationship as the partner may take on a more caring role which can be difficult for both to adjust to if it challenges an existing script (Byng-Hall, 1995). It can cause disruption to family life cycles and challenges to the family system (Carter & McGoldrick, 1999). For some individuals such psychosocial effects and loss of independence have a greater impact than the seizures themselves (Thompson & Oxley, 1993).

1.6 Onset of epilepsy in adulthood and sense of self

The previous section reviewed the potential impacts of epilepsy. However, at the centre of understanding the experience of living with epilepsy diagnosed in adulthood is the person's story of their experience and their identity, and how this may be affected by the onset of epilepsy. The following section begins with a discussion of identity, adopting a social constructionist, postmodernist position and then moves to the impact of how epilepsy may be understood as a disruption to the anticipated life trajectory and identity.

1.6.1 Self (s) and Identities

Identity is defined in different ways, dependent upon the philosophical and epistemological position taken. The common quest to know who we are has been referred to as the ‘inward turn’ (Crossley, 2000). Reflexive questions such as, ‘who am I?’ are often present within Western popular discourses, which has been argued to be partially attributed to the postmodernist individualistic society in which we live (Giddens, 1991; Taylor, 1989). As stated at the start of this chapter, this research adopts a social constructionist postmodernist position, which in line with the position of Foucault (1972) pertains that there is no fixed self, as opposed to the modernist position of there being a stable ‘true self’ that can be assessed and identified through exploration (McCrea & Costa, 1999). Postmodernist thought asserts that our sense of self or selves is not a fixed unified entity, it is socially and linguistically formed, guided by current and historically dominant narratives and the context in which we are situated (Elliott, 2005). Exploration focuses upon how the self is constructed in different contexts and how this connects to wider narratives rather than upon asserting a ‘static essence’ (Cohan, 1997) or a direct link between language and the individual’s inner world or reality.

The concept of self itself will vary dependent on dominant cultural and societal narratives in which the individual is situated. For example, it may be more collectivist, as is prominent in China, or individualistic, as is more prominent in the West. The narratives one draws from will be present in the narrative identity developed and performed, as suggested by the storied resource perspective (Smith & Sparks, 2008), which advocates the role of both the individual and social relational networks upon identity.

The concept of multiple selves as opposed to a fixed stable identity is reflected in Mead’s (1967) “*looking glass self*” which reflects how our sense of self is in relationship to others and their feedback and also in Ricoeur’s (1984) Latin definition of ‘ipse’ or ‘selfsame’. This is a concept that denotes how identity has permanence through time but does not remain the same through time and context. We will narrate the self differently dependent on context and relationships, as stated by Rachman

(1995, cited in Faircloth, 1998, p.604) “*the identity is no longer fixed but becomes meaningful through different ways in different contexts.*” However, the ongoing self-narrative gives “*a sense of him-or herself as an intentional agent with continuity through time*” (Elliot, 2005, p. 126). This perspective fits with the symbolic interactionist literature (Blumer, 1969) which states that meaning is developed and transmitted through symbolic systems such as language and our identity is performed and developed in interaction with others.

1.6.2 Impact of the onset of epilepsy upon self narrative

Becker (1997) stated that “*order begins with the body*” and Mattingly (1998) spoke of our sense of self being ensured to the sameness of our body. Following such positions it could be argued that an illness such as epilepsy, which strikes our bodies and our core functions, would impact upon how we understand or ‘order’ ourselves bringing the body into conscious awareness (Leder, 1990). This process is complicated by the fact that the actual experience of the seizure is something which has to be heard about through others, as the person does not have conscious awareness of their bodily functions. Hence, part of the narrative is authored by another.

Chamaz (1983) spoke of onset of chronic illness as questioning a person’s self-worth. This is highlighted in a quote of a participant in Velissaris *et al* (2007, p. 235) research on the impact of an initial epileptic seizure who stated, “*it makes me feel second rate as a person. Like I’ve lost something. I don’t know what.*” With epilepsy, as section 1.4 described, there is still a strongly perceived and sometimes enacted stigma which may be a significant component in the impact diagnosis has upon the individual and their sense of identity (Scambler & Hopkins, 1986).

1.6.3 Biographical Disruption

Williams (1984, p. 175), in relation to the onset of Rheumatoid Arthritis, spoke of the “*assault [on] an individual’s sense of identity.*” This sense of disruption following the onset of illness is spoken of by Frank (1995, p. 55) as the story “*being wrecked because its present is not what the past was supposed to lead up to, and the future may be scarcely thinkable.*” Bury (1982) spoke of the change brought about by the onset of

illness as ‘biographical disruption’, a term that has subsequently been applied to life disruptions other than illness, such as divorce (Riessman, 2003). Following a study of individuals with Rheumatoid Arthritis, Bury (1982, p.169) argued that the onset of illness led to “*a fundamental rethinking of a person’s biography and self concept*”. The three premises of the theory are that there is disruption to the assumptions a person takes for granted; that the disruption is such that it does not fit with the person’s understanding of their self or their normal means of processing; and that there is action in response to the disruption in ‘mobilising resources.’ Bury (1982) spoke of biographical disruption involving, “*a recognition of pain and suffering, possibly even death, which are normally only seen as distant possibilities or the plight of others*” (p.169). As argued above the onset of epilepsy could cause disruption on all the premises described by Bury (1982) which may lead some people to experience a biographical disruption to the way self is narrated and experienced.

Since the seminal paper by Bury in 1982, the concept of ‘biographical disruption’ has been expanded upon and critiqued, including by Bury himself, with Williams (2000, p. 41) questioning if it “*masks as much as it reveals?*” One of the criticisms of biographical disruption was that it assumed that the person had been healthy or has not encountered such hardship in the past; however, Cornwell’s (1984) ‘hard earned life’s’ study of individuals living in the East End of London, highlighted the importance of considering people’s life experience and social context. Whilst Pound, Gompertz & Ebrahim’s (1998) study suggested the importance of considering the individuals life stage, highlighting that illness may be more ‘biographically anticipated’ in older age (Williams, 2000), and that although the disruption is still experienced it may be less biographically disruptive. This fits with Harris (2009) findings, following a study of people with Hepatitis C, that biographical disruption should not be assumed; it is contextual and dependent on each person’s life experience and meanings of the illness.

A further criticism, voiced by the disability movement, is the tragedy view of disability in which onset of illness is viewed as purely negative (Williams, 2000). It has been shown, in a study of women with chronic fatigue syndrome and

fibromyalgia, an illness which has similarities to epilepsy in the uncertain aetiology and lack of general understanding, that disruption may be partial and focused upon specific areas such as work and social identities rather than across all contexts as the original theory suggests (Asbring, 2001). In addition, research has shown that for some, such ‘disruption’ can lead to growth through existential questioning, reviewing of life and making of life choices. Carel (2007, p. 104) spoke of a ‘creative response’ in relation to personal growth following illness or ‘disruption’. Frank (1995, p. 43) in relation to types of illness narratives, spoke of a quest narrative which entailed “*moments that are privileged in their possibility for changing your life.*” Whilst for others there may be a sense of ‘biographical reinforcement’ (Carricaburu & Pierret, 1995) if the illness affirms part of an individual’s identity or affiliation to a ‘community’ or ‘flow’ (Faircloth, Boylstein, Rittman, Young, & Gubrium, 2004) if the illness and its meanings integrate with existing narratives. These studies highlight how the impact upon identity will be dependent on many contextual factors and cannot be assumed to be purely due to diagnosis itself.

1.7 ‘Adjustment’ or the ongoing process of making meaning of a changing experience?

1.7.1 ‘Adjustment’

The onset of epilepsy could be argued to require the individual to ‘adjust’ to the changes they are facing. Lazarus (1969, p. 18) stated that “*adjustment consists of the psychological processes by means of which the individual manages or copes with various demands or pressures.*” In medical literature on illness there is often an emphasis on adjustment and a focus upon finding factors which may aid or hinder this process. Literature also focuses upon how to measure ‘adjustment’ which is often linked to current societal values- for example, being able to work or being independent. However, for some people with epilepsy these values may remain out of their grasp, so they never attain this position of ‘adjustment,’ and it is argued that their journey cannot be quantified by such measures. Perhaps a more attainable and

appropriate goal in epilepsy would be “*maintaining a sense of value and meaning in life, in spite of symptoms and their effects*” (Bury, 1991, p. 461).

‘Adjustment’ or the person’s journey with epilepsy may be affected by the individual’s perceptions of societal and family views of epilepsy and ability to manage the social and personal implications of these. In a study of people with epilepsy Schneider & Conrad (1981) distinguished typologies of experience. These differed from medical typologies due to their focus upon the meaning of epilepsy to the individual and how they live with it rather than on symptoms. They identified two broad typologies: ‘adjusted adaptation,’ which describes epilepsy as if it had little or no impact due to the management strategies used, and ‘unadjusted adaptation’ in which people feel ‘overwhelmed’ and hide their condition. They found that the adjustment style of an individual was associated with the meaning of epilepsy to that person and how they were able to manage the social and personal implications of the condition. This resonates with Radley & Green’s (1985) model of adjustment, which saw the process as a need to “*resolve the competing demands of bodily symptoms and those of society*” (Radley, 1994, p. 152).

The journey with epilepsy may involve constructing illness narratives which predominantly focus on adjustment and normality so as to be more ‘socially accepted’ (Smith & Sparks, 2008) highlighting the social nature of the illness experience (Schneider & Conrad, 1983). Goffman (1963) spoke of this in terms of differences in individuals’ social and personal identities. Chamaz (1987) also referred to this with her concept of the ‘supernormal self’ which is “*a personally valued and socially credited identity in conventional worlds*” (1987, p.296). A person may construct a restitution narrative, as this is more ‘culturally preferred’ and accepted (Frank, 1995). This highlights the socio-cultural and political aspect of illness which impacts upon the narrative told and the person’s illness experience.

1.7.2 The Changing experience

Living with epilepsy is a changing experience, someone may not have seizure activity for many years and fit with a definition of ‘adjusted,’ but then may have a seizure and find themselves adjusting, coping and living with active epilepsy again. Frank (1995,

p. 9) drawing from Sontag's (1978) notion of 'dual citizenship' spoke of this dilemma within the concept of being a "*citizen of two kingdoms*," both the healthy and the ill. However, this may also present a false dichotomy of only being able to be healthy or ill but one can have health within illness (Lindsay, 1996). For example, Stuifbergen (1990) found that 73% of participants rated themselves as healthy even though living with a disability, highlighting that it does not have to be an 'either or', it can be, as the school of systemic therapy may reframe it, a 'both and' experience (Watzlawick, Weakland, & Fisch, 1974).

Living with epilepsy or 'adjusting' needs to be conceptualised within a dynamic model. An example of such a model is Paterson's (2001) shifting perspectives model of chronic illness which followed from a metasynthesis of 292 qualitative research studies of experiences of adults with chronic illness. The model is focused upon the ever-changing relationship between the individual and the illness. In contrast to trajectory models (Glaser & Strauss, 1964), which have a fixed end point, this model posits adaptation within a dynamic process of how the individual understands and experiences their illness across time as may be experienced when living with epilepsy. The model sees adaptation as a dynamic, not a static or stage-related, process. The model distinguishes two overlapping perspectives- the illness in the foreground, and wellness in the foreground. The author describes how a perceived threat to control can cause a shift in perspective. Epilepsy is characterised by a loss of control and external locus of control (Rotter, 1954). This may mean, according to this model, that any felt or experienced loss of control would place the individual within the illness perspective. Conversely, in times of stability or remission they may be in an 'illness in the background' position. This model captures the dynamic experience of living with chronic illness; however, it fails to consider the role of cultural and societal narratives and the impact of these in causing a shift in perspective. In addition, it does not consider the role of immediate context and how this itself may lead to the construction and performance of different narrative positions.

1.8 'Making meaning' following the onset of chronic illness

In the face of such uncertainty and potential biographical disruption, making meaning has been argued to be a key process in adaptation (Lee & Poole, 2005). As stated by Frank (1995, p.1), after an illness there is the need to *“to think differently and construct new perceptions of my relationships to the world.”* Janoff- Bullman’s (1992) assumptive world theory positions this as the need to restore meaning through the reassessment of shattered assumptions, as may occur following the onset of illness. Whilst narrative theory speaks of the importance of the development of ‘thicker’ stories which allow for continuity of self across times (White & Epston, 1990).

Taylor (1983, p. 1161) proposed a cognitive adaptation model, which argued that the *“process of adjustment centred around three themes: a search for meaning in the experience; an attempt to gain a sense of control or mastery over the illness; and an effort to restore self-esteem.”* The search for meaning involved both trying to understand a causal reason, and also understanding the meaning of life now. It was the latter, Taylor stated that often leads to a new attitude to life, or what others may term ‘post-traumatic growth’ (Tedeschi & Calhoun, 2004).

The biographical disruption of illness can pose existential questions and disruption to assumed narratives of the self, which may lead the person to reconstruct their narrative to develop one which has meaning and continuity across time (Hyden, 1995; Murray, 2003). Bury (1982, p. 175) stated that *“making meaning involves an examination of the constellation of familial and biographical experiences.”* Williams’ (1984, p. 177) study of people living with Rheumatoid Arthritis used the term ‘narrative reconstruction’ as an attempt *“to establish points of reference between body, self and society and to reconstruct a sense of order from the fragmentation produced by chronic illness”*. Williams(1984) explored how people linked their illness to different factors to seek meaning out of the experience. He noted how, from an open question about Rheumatoid Arthritis people linked this to a deeper biographical question of why they had developed Arthritis and the meaning they had made of this. Williams spoke of adaptation and adjustment as a process of *“repairing ruptures between body,*

self and the world” (1984, p.197). For Williams the experience of living with illness was a process of understanding through ‘narrative reconstruction’ which, as his participants displayed, is influenced by many contextual and individual factors but is, he would argue, central to the person’s experience.

1.9 The individual’s experience of living with epilepsy in adulthood:

Traditionally the focus of research on epilepsy has been on the measurement of symptoms or differences in comparison to the general population. These studies offer a means to classify experience into possible trajectories that are useful for medical treatment and understanding. However, these approaches are, as Jacoby (2004) states, “*extrapolating certain common patterns*” (p.24) and are “*limited by resting on research relating to groups of patients rather than individuals*” (p.24). They adopt an ideographic rather than nomothetic approach, and it is argued that this can “*obscure the individual*” (Elliott, 1995, p.117) and “*neglect the individual as an active agent*” (Elliott, 1995, p.122). In such positions the individual and their subjective experience is lost to a generalisation of experience (Andermann, 2000).

To date there have been fewer purely qualitative than quantitative studies of the experience of living with epilepsy in adulthood. Qualitative studies have enabled the range of individual experience, both within and between individuals to be highlighted. Raty, Larsson, Starrin & Wilde Larsson’s (2009) study focused upon the meanings of epilepsy as a concept to nineteen people with epilepsy. They found varying meanings from: epilepsy as an illness related to physical disturbances; in which epilepsy is defined as something with a known medical explanation to epilepsy as a handicap in relation to associated psychological and social implications. As would be expected, they reported that emotions associated with epilepsy varied with the meaning of the illness to the person. This highlights the varying meanings that the illness can hold and the impact of these upon the person’s understanding.

Faircloth’s (1998) study of three epilepsy narratives sought to highlight the “*divergent and peculiar nature of the epilepsy experience*” (p, 603), while Nijhof (1998) spoke of the heterogeneity of interpretations within individuals; arguing that individuals make

multiple interpretations of their experience, and these change over time. In a study of twenty people with epilepsy Nijhof found that the medical discourse was often seen close to the period of diagnosis, however, that this faded and most people distanced themselves from this with time. Nijhof (1998) also spoke of how the concepts of normality or abnormality seemed to be linked to whether the individual was talking of interpretations of the self or of others, highlighting the social nature of the illness experience. However, whilst Nijhof (1998) and Faircloth's (1998) papers highlighted the range of experiences they were criticised by Andermann (2000) for their neglect of focus upon the context in which the narrative is situated. This is also a limitation of Raty *et al's* (2009) study which did not consider the narratives participants may be drawing from and their role in construction.

The role of family and cultural narratives in understanding experience was highlighted in Good & Del Vecchio Good's (1994) study of narratives of individuals and their families in Turkey. They spoke of the multiple perspectives held by people with epilepsy and their families and how these may be influenced by cultural beliefs about healing and epilepsy. The paper focused upon the way people used 'subjunctivising modes' within language to "*justify continued care-seeking and maintain hope*" (Good & Del Vecchio Good, 1994, p.835) also identifying the role of power relations in the narrative co-constructed within families. Small *et al's* (2005) study spoke of the range of understanding of epilepsy held within Bradford's South Asian community. The paper highlighted how an individual's understanding shaped their management and disclosure. Furthermore, the paper demonstrated how this understanding was related to a multiplicity of beliefs, often with Western narratives of causality co-existing alongside spiritual narratives. Such studies are able to highlight the complex relations and understandings of epilepsy that impact upon a person's understanding, their experience of living with the condition, and their access to NHS health care. They are also extremely valuable in developing clinical understanding of beliefs and their role in health behaviour.

The role of societal, historical and cultural narratives of epilepsy, in particular stigma and its impact upon individual experience, has been explored by several qualitative studies. Recently, Kilnic & Campbell (2009) conducted a study of 30 people with

epilepsy that focused upon their experience from diagnosis onwards. The three themes that emerged; misconceptions versus ownership, avoiding versus sharing and embarrassment versus normalising, resonate with early studies of stigma (Schneider & Conrad, 1980) and the method of coping by concealment spoken of in Ipohen's (1990) case study of a lady with absence seizures. In Ipohen's study the participant spoke of managing her social identity and relationship so as to conceal her epilepsy, a concept Goffman referred to as '*passing*'. Schneider & Conrad's (1981) study which identified typologies, focused upon meaning and consequences rather than seizure activity, and spoke of concealment or honesty as one of the factors defining typologies. However, in Admi & Shaham's (2007) study, participants' experiences showed a different perspective to the dominant narrative of stigma and epilepsy, advocating for a normalcy model of "*ordinary people living with extraordinary circumstance*" (p.1187). They found that the stigma of epilepsy was not the central theme in the individuals' lives as traditional stigma theories and the Kilnic & Campbell (2009) study may suggest it would be. However, in the audience selection theme it was clear that concealment is still evident in the epilepsy experience, with only three participants telling everyone and one participant out of the sample of fourteen only telling their brother. The participants' experiences also highlight the role of family narratives and beliefs upon experience, with one participant speaking of being expected by family to keep the epilepsy a secret.

These studies highlight the ability of qualitative studies to enable us to hear the subjective and different experiences both within and between individuals. Illness narratives, despite criticisms of the risk of over-romanticising illness (Frank, 1995) offer valuable insights into the experience of living with illnesses and highlight that the person's experience is more than the measurement of their symptoms. However, all narratives need to be considered within their context, and this includes the way in which the narrative is told, in addition to the immediate and wider context in which the narrative is situated (Riessman, 2008). A criticism of all of the reviewed studies is their neglect to focus upon why a story may be constructed in a particular way and the rhetorical work a person may be doing to perform a particular narrative in that particular research context. This ignores important information that is crucial to

understanding the experience of living with epilepsy, its meaning to the individual, and how it is managed. Studies focused upon both what is told and how it is told are crucial to widen our understanding of the experience, and how meaning is made, guiding knowledge through detailing the local context. A narrative exploration of living with epilepsy offers a valuable insight into lived experience in order to develop holistic understanding which will inform improvements in clinical practice.

1.10 Clinical Relevance

People's subjective experience is often more valuable to developing understanding of experience than statistics, which describe experience in relation to what would be expected for a given population. Jacoby & Baker (2004) comment upon the growing quantitative evidence of the impact of epilepsy upon quality of life, but question whether quantitative studies can "*shed light on the process*" (p,6) of the lived experience which is important for developing clinical care (Bishop & Allen, 2003) and a more holistic focus of care (Department of Health, DOH, 2005).

Narrative research can help to better understand cultural beliefs linked to health behaviours (Eardley & Elkind, 1990; Small, et al., 2005; Wood, Jewkes, & Abrahams, 1995). Narrative studies allow exploration into the process of living with an illness at a local and societal level which quantitative studies may not be able to access. This is important information to aid clinical understanding and management of what support maybe needed at different stages of an illness experience. Asbring (2001) stated that it was this information which could facilitate encounters between professionals and people with illnesses. Andermann (2000) stated that narratives "*form an important counterpoint to the growing international body of epidemiological data on this illness which, while of great importance, is measured on a societal level and leaves out the richness of the local experience*" (p,172) .

In an illness still shrouded in mystery and misconceptions a narrative exploration can aid general, as well as clinical understanding, of the subjective experience of being diagnosed with epilepsy in adulthood and how it is experienced over time.

1.11 Summary and aims of research

Epilepsy is the most common neurological disorder in the UK (Stokes *et al*, 2004) and is associated with a range of psychological disorders and depressed quality of life trajectories (Jacoby, 2004). It is a disorder that has been commonly misunderstood and is still laden with beliefs, often negative, that differ from the medical narratives and can impact upon the person's experience and the narrative constructed. For individuals diagnosed in adulthood, this new experience and all it entails can have a profound impact upon both how they live their lives, and how others and they narrate their identity.

This study aims to better understand the experience of being diagnosed with epilepsy in adulthood, through hearing the narratives of people living with epilepsy and considering the ways in which these are constructed and told to an outsider and how the outsider influences the narrative. It is hoped that this will deepen understanding of this life-changing experience, and help health professionals and others to provide better understanding and support.

1.12 Research questions

The main research question is how do individuals living with adult diagnosed epilepsy describe their experiences?

From which additional questions are:

How do these narratives describe and account for:

the changing individual relationship with epilepsy over time? And

the changing relationship to self and others over time?

CHAPTER 2. METHODOLOGY

This chapter will begin by describing and providing a rationale for the research methodology. It begins with the justification for using a qualitative methodology and then moves onto the theoretical framework underpinning this research and the reason for, and type of analysis chosen. It then has a section describing the importance of reflexivity, how this was maintained within the research process and an overview of the researcher's position. The chapter then moves onto a thorough explanation of the design of the research. The detail and transparency of the process enables the reader to assess the suitability of the design and chosen representation of the analysis. The chapter concludes with an explanation of the measures of trustworthiness, rigour and credibility which offer the reader a means to evaluate the credibility of the research.

2. 1 A qualitative approach

This research aims to hear the experience of living with epilepsy in individuals diagnosed in adulthood. The research has an exploratory focus seeking to capture the diversity of individuals' experiences. A qualitative idiographic methodology has been adopted as this highlights rather than conceals the individual and enables a 'thick description' (Geertz, 1973) of people's experiences to be heard.

To date the majority of research on the experience of living with epilepsy has adopted a quantitative methodology which casts a shadow over the individuals' experience in favour of developing objective information on expected trajectories of experience. Whilst such research is of value, there remains a paucity of research that focuses on hearing the individual's experience as they tell it. Such research is vital to broaden understanding and knowledge about the experience of living with epilepsy, both for clinicians to inform practice, and those living with epilepsy to have a diversity of narratives to draw from (Jacoby, Gorry, Gamble, & Baker, 2004; Smith & Sparkes, 2007).

2.2 Theoretical framework

At the start of the introduction the guiding philosophy and epistemological position underlying this research was introduced to set the context in which the study was

conducted. Postmodernism and social constructionism are at the heart of this research in how it was conceived and conducted. In this section, each is considered in turn, detailing why it was chosen and its applicability to the research questions.

2.2.1 Postmodernism

Postmodernism opposes the positivist position that “*there is a reality out there to be studied, captured and understood*” (Denzin & Lincoln, 2000, p.9) and adopts the position that there is no one objective reality that is consistent and able to be measured. Postmodernism views reality as constructed by individuals seeking to make meaning out of their world and experience. Gergen (1994, p.412) spoke of “*the abandonment of the traditional commitment to representationalism,*” in that people’s talk about their ‘experience’ cannot be taken as a direct representation or description, since it is shaped by constructions of the event, context and interaction. It is not a fixed story or ‘truth’ but an ever-changing construction of their experience. Such perspectives of subjectivity and consideration of wider narratives, including political agendas, has been criticised for not being of value in scientific investigation (Greenfield, 2005) however it is its ability to highlight multiplicity and not categorise within a positivist framework that is of value in this research.

Lyotard (1984, p.xxiv) spoke of postmodernism as “*incredulity towards meta narratives*” and a focus on the smaller local narratives. Consistent with the aims of this research, postmodernism places value on hearing the less dominant narratives. Adopting a postmodernist framework enables the multiplicities of meanings and interpretations held within a story to be considered and local narratives that may not fit with meta narratives to be heard (McAllister, 2001). The importance of this is highlighted in previous research into epilepsy, which has shown there can be many different narratives held within a family and by individuals, and this is an important consideration in health behaviour and understanding the experience of living with epilepsy (Good & Del Vecchio Good, 1994; Small, et al., 2005).

2.2.2. Social Constructionism

Social constructionism adopts the position that all knowledge is constructed through the use of linguistic structures or symbols in social interaction (Berger & Luckmann, 1966). In line with postmodernism, social constructionism advocates that knowledge is not a fixed entity and there is no one objective truth; instead meaning, power and knowledge are constructed in social interaction through language and are ever-evolving (Burr, 2003). All knowledge is socially constructed in interactions with others, and our understanding is guided by available meanings held within the social relationships or circles we engage in.

Gergen (1985) spoke of four defining features of social constructionism, which are central to this research. The first of these is the rejection of an objective truth and acknowledgement of the subjectivity of experience and the role of language in its construction. Connected to this is the notion that the researcher is not neutral and objective, but part of the process in the construction of the narrative and the meanings made of it. This is reflected in the central role of reflexivity within the research process through the use of a reflective diary, reflective notes within the analysis, and a section on reflexivity to make the researchers position clear.

Secondly, social constructionism places a central role on historical and cultural specificity in the meaning and narratives constructed. The importance of this within the field of epilepsy was detailed within the introduction in relation to the historical meanings of epilepsy and how historical and cultural narratives can impact upon how epilepsy is understood by the individual and the narratives constructed. Thirdly, Gergen spoke of the central role of language in constructing knowledge through interaction with others, and how language can hold different meanings in different contexts. Finally, Gergen stated that the social nature in which knowledge is constructed and maintained as reality, and our sense of self, are socially constructed and sustained in social action. The latter two are reflected within the analysis chosen, which focuses upon both what was said and how it was constructed in that context, considering why and how it may be constructed differently in different contexts and times.

2.3 The case for Narrative and Narrative Analysis

Narrative has been argued to be the central means of human sense-making (Murray, 2003; Polkinghorne, 1988). It offers a means of linking experience across time and providing a sense of order and coherence (Bruner, 1990; Ricoeur, 1984; Sarbin, 1986). Sarbin (1986) argued that we are born and socialised into a storied world, and it is through these stories that we create a narrative identity (Ricoeur, 1988). As stated by Reissman (1993, p. 2) “*individual’s construct past events and actions in personal narratives to claim identities and construct lives.*” Narrative allows “*retrospective meaning making*” (Chase, 2005, p.656), indicating they are more than a relaying of facts; they also express the narrator’s point of view and are an action, or a call for social action (Reissman, 2008).

Reissman (2008, p.116) defines narrative as “*a bounded segment of talk that is temporally ordered and recapitulates a sequence of events.*” Narratives offer a means to explore the way individuals have made sense of a particular experience, whilst acknowledging this will not be factual representation of the event but a “*recipient-designed*” (Reissman, 1997, p. 156) construction of the event and its meaning for that person, in that context and to that audience. As stated by Murray (2003p,116) “*narrative accounts are not emitted in a vacuum; rather are encouraged and shaped by certain social context*” and are both co-constructed and performed (Wells, 2011).

Narrative analysis is an umbrella term for a variety of interpretive approaches that focus upon texts or materials which “*have in common a storied form*” (Reissman, 2008, p. 11) as their unit of analysis or focus of exploration. This unit of analysis was chosen as it highlights “*how people make sense of their worlds*” (Smith & Sparkes, 2009, p. 281). It was also chosen as it is often at points of change, such as the onset of epilepsy, that narrative may be used to make sense of this experience (Becker, 1997). It enables consideration of how and why a story is co-constructed in a particular way, what identity is being constructed, and how this may link to dominant narratives and social contexts (Plummer, 2001). Narrative analysis also fits with the temporal nature of epilepsy, which is not acute and short lived, but experienced over time, which fits with the emphasis upon temporality within narrative analysis (Cortazzi, 1993).

Narrative analysis has many different methodologies and definitions (Riessman, 1993). Georgakopolou (2006, p. 123) spoke of the movement in narrative analysis within a wave analogy, stating that there has been a move “*from the study of text to the study of narrative-context.*” This depicts the movement from a purely structural focus, as Labov & Waletzky (1967) originally advocated, to consideration of the process of construction and the role of the context in which the narrative is situated.

Goffman (1959), in his dramaturgical analogue, speaks of people as actors performing identities within conversations. Related to this, Mattingly (1998p.8) speaks of how “*narratives do not merely refer to past experience but create experiences for their audiences.*” This suggests that there is more than the text to consider, there is also how it is shared or ‘performed’ and the role of the interview context in its shaping (De Fina, 2009). Smith & Sparks (2009, p. 281) refer to this as “*dual focus*” of analysis, looking at both how the text is constructed and what is said. The consideration of the narrative-context is central to this research and the underlying epistemological position. Given the plurality of narratives of epilepsy held by individuals and within society, all of which may impact upon a person’s narrative, it was felt important to analyse both the content (what was said) and the construction or performance (the how) of the individuals’ narratives in this research. In addition, applying multiple complimentary analyses adds to the depth of the analysis (Smith & Sparks, 2009).

2. 4 The choice of Narrative Analysis rather than other qualitative methodologies

For the reasons discussed, it was felt to be important to consider the narrative in context, including analysing the rhetorical work in the construction. This is a feature distinguishing narrative from phenomenological approaches such as Interpretive Phenomenological Analysis (IPA) which have been criticised for “*uncritical presentation of their understanding of a phenomenon*” (Yardley, 1997, p. 30) through applying a ‘chain of connection’ between what a person says and what they feel or think. Discourse analysis was discounted as its focus is upon the use of language not on the wider context or social meanings people may be drawing from (Burr, 2003). Grounded theory was ruled out, as it seeks to generate a theory (Glaser & Strauss, 1964) and thereby generalise a unique experience, not “*giving justice to the richness*

of experience” (Saukko, 2000, p. 312) which did not fit with the research aims. As stated by Burck (2005, p. 265) “*narrative analysis helps the researcher to examine issues of self-presentation in an overall way, which a grounded theory and discourse analysis miss through their focus at a different level.*” Thematic analysis did not fit with the focus upon context in co-construction or on understanding the individuals experience rather than the number and type of themes (Krippendorff, 2004).

Narrative analysis within a social constructionist postmodernist framework was chosen over other qualitative methodologies as it allows the multiple meanings and their link to wider narratives to be considered, in addition to the role of context in the stories development and performance which was felt to be important in the context of an illness that carries many meanings.

2.5 Reflexivity

Within a postmodernist social constructionist framework knowledge is seen as subjective with the possibility of multiple realities. The researcher’s assumptions and position cannot be separated from the research process, either in the co-construction of the narrative in the interview or in the analysis (Mishler, 1986). Any interpretation reflects the researchers position and beliefs and is not value-free or objective it is situated and relative (Taylor, 2003). Consequently, reflexivity is a crucial part of the research process, as is making clear to the reader the researchers’ position and how this impacted upon the interpretations made. Reflexivity was a constant part of the research process, aided by the use of a reflective journal and reflective notes within the analysis process.

2.5.1 Self-reflexivity

I had an interest in people living with chronic illness, but had had little exposure to working with individuals prior to commencing clinical training. My main understanding was guided by bio-psycho-social models of living with illness, from which I was aware of the social and psychological impacts of living with illness, but less so of the impact upon a person’s identity in relation to how they see themselves and how they are seen by others and within society. As introduced at the start of this

thesis, I developed an interest in epilepsy following clinical work with a woman of a similar age, ethnicity and educational background to myself, who had developed epilepsy in adulthood. I think it was her emotional story of disconnection to the 'self' and the similarities between myself and the woman which led this case to resonate with me so personally. It led me to reflect upon what my story would be if I had come into the same circumstance. I am a thirty-one-year-old white female of a middle-class background who has not experienced any serious health concerns. I tend to take my health for granted, and hearing this woman's story of someone who had also never thought about her health until it was under question, made me think about how I would experience this change and disruption to my expected life course.

The interest in this case led me to research further into epilepsy. I was struck by the range of narratives held both currently and historically. I was also struck that my own faith historically, in some denominations, held such stigmatising beliefs which could lead a person with epilepsy to be seen as lesser, or with less rights relative to 'healthy' people. The more I read about epilepsy the more interested I became in how it historically and currently held such a range of predominantly stigmatising narratives, despite there often being a clear biomedical explanation, and how these narratives impacted upon the stories told by the individual and their meanings of epilepsy. This interest in narratives of epilepsy and their impact upon experience is one of the lenses through which this research was conducted.

Professionally I am an employee of the NHS and a trainee clinical psychologist. Emerson & Frosch (2004) have spoken about the influence of your professional identity upon the research process and Lieblich, Tuval-Maschiach & Zilber (1998) have spoken about the difficulties of this balance. I was aware during the interviews and the analysis of trying to balance the dual role of being a researcher and a therapist. I used the support of my supervisors and my reflective diary to help me to remain aware of this dual role.

I also hold the dual role of being an employee of the NHS and an academic student. I was aware that my role as an employee of the NHS and a representative of health services may have positioned me in a particular way to some participants, impacting

upon their narrative. This is something I reflected upon and is considered as part of the analysis in relation to the context of the interview in which the narratives were co-constructed.

2.6 Participants

2.6.1 Sampling strategy

A purposive sampling strategy was adopted to recruit a maximum of eight individuals. This sample size was decided upon due to the detailed and rich information gathered within narrative research (Wells, 2011). The inclusion criteria were that:

- the individual was diagnosed with Epilepsy in adulthood(18+);
- they have had a diagnosis for at least one year;
- they had been diagnosed within the last 20 years;
- they have had seizure activity in the past year; and
- they are able to speak English fluently

These criteria were chosen so that individuals have had some time since diagnosis to be able to share a narrative of the meaning of having epilepsy and their journey with the illness, in addition to being able to talk of the relationship between self and epilepsy over time and still be able to recall life prior to onset. The criteria of being able to speak English fluently was included as meanings within the narrative might have been lost if they had to be translated or unable to be shared if the person did not have the English to be able to verbalise what they wanted to share.

The exclusion criteria were:

- Co-morbidity with an Autistic Spectrum Disorder, learning disability, non-epileptic attack disorder, psychosis, or having any other neurological disorders alongside epilepsy, which were present prior to onset.
- Individuals also needed to be in a stabilised condition receiving routine community care.

These criteria were decided upon to allow a sole focus upon the experience of living with epilepsy in adulthood and so that individuals could safely engage in the research.

2.7 Recruitment

Participants were recruited through Epilepsy Action and the National Society for Epilepsy. A research application was submitted to Epilepsy Action. This application requested that information on the research (Appendix C) be placed on the research page of their website and shared with the London, Hertfordshire and Essex support groups. Approval was granted (Appendix D) and information was circulated onto all of these modalities. A request to circulate information on the research was also submitted via email to National Society for Epilepsy, who agreed to place the same information on their website volunteer page (Appendix E).

All potential participants who made contact to enquire about participating were sent an information sheet (Appendix F). The sheet advised that, if after reading it, they had any questions or wanted to volunteer to participate, to contact the researcher. All potential participants who volunteered to take part were asked the same screening questions to ascertain if they met the inclusion criteria. This process was stated on the participant information sheet. People who made contact but did not meet the criteria were thanked for their time and given an explanation as to why they had not been asked to participate. People who volunteered to participate who did meet the inclusion criteria were sent a consent form (Appendix G) to read through, and asked to get in touch if they had any questions. If they agreed to the conditions of consent, a date and location for the interview was agreed. The consent form was reviewed and signed before the interview started.

Participants were sent a background information sheet (Appendix H). This sheet requested basic demographic information, details of their epilepsy and its medical management. This form was sent out to all participants to enable the collation of demographic information to “situate the sample” (Elliott, Fischer, & Rennie, 1999). Participants were informed that questions were optional and they did not have to complete the form to be able to participate in the research. The details shared are shown in Table 1.

Table 1: Sample Demographics

Pseudo Names	Katie	Sarah	Claire	Vivian	Melanie	Martin	Emma	Richard
Age	29	33	27	54	30	52	48	77
Ethnicity	White British	White English	White British	White British	White British	White	White British	White West Indian
Religious Affiliation	-	-	-	Church of England	-	Roman Catholic	Jewish	Methodist
Diagnosis	Probable Temporal lobe epilepsy	Epilepsy and Paroxysmal Dyskinesia	Tonic Clonic Seizures	Temporal lobe epilepsy	Refractory temporal lobe epilepsy.	Temporal lobe epilepsy	Epilepsy	Tonic clonic Seizures
Age when diagnosed	28	29	18	44	26 & 29	42	35	75
Most recent seizure activity	June 2010	End of 2009	July 2010	May 2010	June 2010	March 2010	July 2010	February 2010
Age at first seizure	15*	29	18	44	26	42	34	75
Marital Status	Single	Married	In a relationship	Married	In a relationship	Single	Single	Married

*This is the age at which Katie first experienced déjà vu's which she associates to her epilepsy.

Fifty-nine people volunteered to participate, of which fifty-two met the inclusion criteria. Participants were selected on the basis of who got in touch first. Once all eight participants had been recruited any further requests to participate were thanked for their time and interest and informed that recruitment was completed.

2.8 Ethical considerations

Ethical approval was granted by the University of Hertfordshire (Appendix B), following confirmation from the National Research Ethics Service that this research did not require their approval as participants would not be recruited through the NHS. Guided by the British Psychological Society code of ethics (2009) conditions of informed consent, confidentiality and participant well being were adhered to as detailed below in developing and conducting this research.

2.8.1 Informed consent and confidentiality

Informed consent was ensured through the provision of the information sheet to anyone who expressed an interest in the research (Appendix F). This sheet gave an introduction to the research in addition to information on consent, confidentiality and the exceptions to this, possibility of distress, and potential benefits of participation. This information was intended to help the participant to make an informed choice as to whether they wished to take part, and if so, consider what support they might need to look after themselves. If they decided to volunteer they were sent a consent form which detailed the conditions of consent and confidentiality (Appendix G). The information sheet and consent form were reviewed prior to the interview starting. If in agreement, the consent form was then signed by both parties.

2.8.2 Participant well being

If a participant became distressed during the interview the researcher used her clinical experience and skills to be empathic, listen and contain the participant's distress. The person was reminded that they could take a break at any time, choose not to answer questions, or stop if they wished to.

At the end of the interview participants were given the opportunity to ask any questions they had. The participants were given a sources of support sheet (Appendix I) which detailed organisations that could offer support following the interview, if needed. A follow-up call was offered to all individuals one week later in case of any residual impact which they were unable to talk about or had not yet been processed at the debrief. It was agreed that if the researcher had any concerns about an individual, these would be discussed at the earliest opportunity with the primary supervisor.

2.8.3 Material Presented

An additional ethical consideration was the researcher's power over the data and its presentation (Squire, 2008). Whilst the research aimed to share narratives of living with epilepsy, the material presented in the analysis section is not a pure reflection of the narratives co-constructed but an interpretation guided by the chosen methodology. The researcher has sought to make interpretations that will develop understanding of the experience. It is due to the interpretation within the analysis, and position that narratives are situated in time and context, that participant validation was not sought. However, the participants as potential audiences was held in mind in consideration of the language, interpretation and presentation of analysis (Clandinin & Conolley, 2000). Participants were sent the shared plots and storylines, enabling them to see the similarities and diversities of experiences shared, and asked to give feedback if they had any, but the researcher held interpretative responsibility (Squire, 2008). The researcher diligently used the checks detailed in a later section to ensure rigour, credibility and trustworthiness.

2.9 Data collection

2.9.1 Interviews

Individual interviews were chosen to hear the experiences of living with epilepsy, as is commonly used within narrative research (Mishler, 1986; Murray, 2003). The interview aimed to invite people to 'tell their story' through open rather than directive questions. All interviews started with the same general open question, which was based upon that used within Thornhill, Clare & May's (2004) narrative exploration of

the experience of recovery from psychosis. The researcher aimed to follow the participant's path 'actively listening' (Kvale, 2007) to encourage their narrative and minimise directive influence to promote the context of "*two active participants who jointly construct narrative and meaning*" (Mishler, 1986, *as cited in* Riessman, 2008, p.23). Before the start of the interview all participants were informed that when they finished talking a space would be left for them to decide where they would like to direct their narrative next. In all of the interviews at least one of the probes stated within topic guide (Appendix J) was asked. Interviews varied as to which probes were used depending upon the path taken by the participant.

2.9.2 The development of the Interview Guide

As recommended by Riessman (1993) several topics were chosen, with general probes for each. The interview guide topics followed from the research questions and literature reviewed to encourage narratives on the experience of living with epilepsy, the meaning of epilepsy to that person, and if this had changed over time, in addition to any cultural or societal narratives which may have shaped their understanding.

In line with the National Institute for Health Research and INVOLVEs' good practice guidelines (2009) feedback on the interview guide was sought from someone living with epilepsy. A pilot interview was conducted with a volunteer from Epilepsy Action Research Network. The volunteer was a white British male in his fifties who has been living with epilepsy since childhood. Although this would exclude him from participating in the actual research, it was felt it would still be of value for the purposes of getting feedback on the interview prior to the actual study. The interview was conducted and then the volunteer gave feedback on the process of taking part and the questions asked. Sue Usiskin MBE, also gave feedback on the interview questions, drawing upon her years of clinical experience as a specialist epilepsy counsellor in addition to her own lived experience of having epilepsy. Both of my supervisors also gave feedback on the research questions. This feedback led to the final interview topic guide (Appendix J).

2.9.3 Interview Procedure

All participants were given the option of either meeting at their home, which four requested, or at a local university or council library, where a private room was hired. At the start of all meetings the information sheet (Appendix F) was reviewed and any questions participants had answered. The consent forms (Appendix G) were also reviewed and any questions answered before both parties signed the form. All interviews were tape recorded and lasted approximately 60 minutes each.

At the end of the interview the tape recorder was switched off and time was allowed to discuss how it felt to take part in the research, and answer any questions participants had. All participants were asked and confirmed they would like to be contacted with a summary of the general findings of the study.

Immediately after the interview, reflections on the interview process were written within the researcher's reflective journal. The researcher made notes on feelings throughout the interview, thoughts of what felt important to be heard and reflections on the questions asked, in addition to any contextual factors that may have impacted upon the narrative co-constructed.

2.9.4 Interview Context

I am aware that diversity-in the widest definition, both similarities and differences - will have impacted upon the narratives co-constructed, positioning within the interview context and interpretation. In relation to this I found it useful to hold Burnham's GRRAACCESES's (1993) in mind to aid reflection upon how such diversities may have been perceived and played a role in the narratives constructed. GRRAACCESES's is an acronym for gender, race, religion, age, ability, class, culture, ethnicity, education, sexuality and spirituality. It was developed to enhance reflection upon power and difference in systemic clinical practice. The framework was used in this research to aid reflection upon such factors during the analysis. In fitting with the guiding theoretical framework, consideration was also given, throughout the research process, to the power dynamics within the immediate and wider context and how this may have impacted upon the narrative co-constructed. The interview, which

began by introducing my interest in their experience and encouraged their story throughout, re-addresses some of the imbalance that may be more pronounced within more realist research, in which the researcher may be seen as the ‘expert’ (Elliot, 2005). However, power and diversity are recognised as important factors in co-construction and performance; as such, both were incorporated into my analysis of the narratives.

2.9.5 Transcription

It is recognised that transcription is an interpretive act, a representation of the interview guided by underlying theoretical position, and as stated by Riessman (1993, p.11) any “*transcript is incomplete, partial and selective.*” Guided by the position that narrative is co-constructed within a specific context (Riessman, 2008) the interviews were transcribed verbatim including within this the researcher’s involvement as participants responses are part of an interaction. Transcription also included details such as any pauses or conversational characteristics such as laughter as these are viewed as part of the narrative performance. Some of the transcripts were transcribed professionally. Prior to submitting the recordings a confidentiality agreement was signed (Appendix K). Upon receipt of these transcripts they were read whilst listening to the interview, and any necessary amendments or additions made.

2.10 Analysis

2.10.1 Guiding framework

All interview transcripts and recordings were uploaded onto the MAXQDA 10 software which was used throughout as a resource for storing all information (e.g. interview recordings, transcripts, analytical memos) within one location. The narratives co-constructed in the interview were analysed in their entirety not separated into units or categories (Riessman, 2008). Each narrative was initially analysed individually focusing upon the content (what was told) and how it was told (the telling) simultaneously drawing from Gubrium & Holstein’s (2000) ‘analytical bracketing’. This is “*an orientating procedure for alternately focusing on the whats and then the hows of interpretive practice (or vice versa) in order to assemble both a*

contextually scenic and a contextually constructive picture of everyday language- in-use” (p. 500). Combining of methods- looking at both the what and the how- has been argued to be suited to the complexity of narrative which lends itself to multiple methods of analysis to deepen understanding (Smith & Sparkes, 2009).

The analysis combined two narrative frameworks. Firstly focusing upon the content of the narratives I drew from Lieblich et al’s (1998) ‘holistic content’ framework, in relation to viewing the narrative as a whole and analysing storylines in the context of the whole narrative. Storylines are defined as collective themes or positions present across a narrative. The main question within this framework was, what were the main experiences of living with epilepsy that were spoken about?

In seeking to consider “*How does this person, in this context, come to give the account he/she does?*” (Wells, 2011, p.101) and how does he/she do this? I drew from questions developed by several authors (See Appendix L). These questions aided consideration of the narrative at multiple levels from the immediate interview context to the wider context in which the narrative is situated (Murray, 2001); guiding attention to what narratives people may have been drawing from and how the current societal and historical context may have shaped the construction (Riessman, 2003). The questions were not considered in a set order but the researcher held these questions in mind and had them alongside the transcripts during analysis. The questions guiding the analysis came primarily from Riessman (2003). These focus upon how and why a story may have been told in a particular way in that context. For example, in what kinds of stories did the narrator place himself? How does he/she locate him/herself in relation to the audience, and vice versa? In addition, Burnham’s (1993) GRRACCEESS, aided consideration of the impact of diversity upon interaction and the narrative co-construction. Finally, Minister’s (1991, p. 29) ‘who are the ‘ghostly audiences?’’ question facilitated consideration of agenda and what other audiences the narrative may have been constructed and ‘performed’ for.

This guiding framework of considering the content and the telling were applied together fluidly over several readings to enable an in depth immersion into the

transcripts and aid listening for the multiple meanings within each account (Bakhtin, 1981 cited in Riessman, 2008; McAllister, 2001).

2.10.2 The stages of analysis

There were multiple stages to the analysis as befits the complexities and richness of narratives. Each will be detailed in turn, Appendix M has details of each of the stages of analysis with reference to one transcript ¹.

1. The first stage was to read and immerse myself in the narrative. Each narrative was initially listened to at the same time as reading the transcript, to hear the tone and remind the researcher of details in the interaction that may not have been captured in the written transcript. The researcher also read through the reflections written post-interview within the research reflective diary.
2. The researcher then read through the narrative in its entirety several times. During readings notes were written focusing upon both the content and performance of the narrative. At this stage, the researcher focused upon what felt important to be heard, how the story was told and how the narrative was organised in relation to when different stories were told and repetitions of stories or phrases.
3. Once the transcript had been read several times, a ‘global impression’ (Lieblich, et al., 1998) was written. The ‘global impressions’ are both descriptions of the main stories heard and how these stories were told, as interpreted by the researcher. This aided the researcher in summarising the initial interpretations of the narrative.
4. The narrative was then read listening for the storylines. Storylines, defined as collective themes or positions, were identified by the strength of their presence or perceived importance of being heard as interpreted by the researcher. These could be a particular theme, or a position adopted within the narrative. The process guiding the identification of storylines and their meanings were discussed with supervisors and within the narrative peer supervision group.

¹ For purposes of confidentiality, the transcript will only be included within the examiners copy.

5. Once storylines had been identified, they were each considered individually, focusing simultaneously on the ‘what’ and the ‘how’. The content questions were guided by the ‘holistic content’ framework(Lieblich, et al., 1998), which suggests consideration of where a storyline first entered the narrative, where it left, exceptions to the storyline, and contradictions. Alongside these questions the researcher considered the performance questions. Throughout this process, memos were written recording this process and quotes particularly associated with a storyline were highlighted on the transcript.
6. Brief narratives were written for each storyline.
7. This process was completed for each participant’s transcript in turn.
8. Once all eight narratives had been analysed individually, they were considered collectively, focusing upon similarities and differences of storylines. In considering the narratives collectively, the focus was still upon both what was told and how it was told. This enabled bracketing of stories under broad umbrella plots, beneath which individuals might adopt similar or distal positions in either the content of the story or how it was told.

The shared plots were identified through reading of the transcripts and individual narratives. All participants spoke about the onset, although their positions and stories told varied. People also spoke about the changes of living with epilepsy. In addition, people spoke of the meanings of epilepsy both to themselves, others and within wider society and the impact of these upon their experience and management of epilepsy. Very broad umbrella plots were purposely chosen to enable consideration of varying positions, the storylines, rather than seeking to present ‘neat’ categories. Hence plots were viewed as organising frameworks rather than rigid categories. The move to considering narratives collectively enabled presentation of epistemological narratives (Harling Stalker, 2009) which “*connect events in meaningful ways for a particular audience*” (p.222). Beneath the shared plots, storylines enabled presentation of the varying positions and experiences within participants accounts. This means that each participant is represented in each of the shared

plots but not in each storyline, fitting with the aims to highlight heterogeneity of experience.

2.11 Representation of narratives

Once analysis was completed the decision as to how to represent the narratives was made. The richness of the narratives presented challenges in how to give each participant's account justice and also present the reader with a coherent analysis, within the word limit. In accordance with the aims highlighted in the introduction, it was decided that the representation of narratives should begin with the individuals. The analysis begins by introducing each person to the reader and then giving a 'global impression' (Lieblich et al., 1998) of their narrative, as interpreted by the researcher. These are written in the third person to position them as the researcher's interpretation (Saukko, 2000). Quotes are woven into the researcher's interpretations for purposes of transparency and persuasiveness (Riessman, 2003; Yardley, 2008). The "*stitching together*" (Sauuko, 2000 p.300) of quotes with the researcher's interpretation and links to wider narratives aims to situate the interpretations. This presentation is also reflective of how the participants are drawing from wider narratives and of the co-constructed nature of the accounts (Sauuko, 2000).

Next the collective narratives are presented. The presentation of both the individual 'global impressions' (Lieblich *et al.*, 1998) followed by the collective plots will be of most clinical use in enabling the reader to see the diversity as well as the similarities in experiences and positions. The analysis and discussion are presented together in line with the epistemological position that the 'results' are not objective, they are interpretations and it not therefore suitable to create an artificial distinction between 'results' and 'discussion'. The joint presentation creates a coherent narrative for the reader which contextualises the researchers interpretations, the links to grand narratives as well as the contrasts and extension of existing literature. This presentation also reflects the position that all narratives draw from wider narratives and are situated in a time and context (Murray, 2001; Wells, 2011).

2.12 Rigour, credibility and trustworthiness

The traditional notion of validity and reliability are based upon positivist assumptions of a one known identifiable truth which does not suit a narrative qualitative study. Narratives can be read in many ways and are always situated in ever changing contexts and wider narratives (Riessman, 2008). The researcher is not seeking to verify accounts to a known truth, as set out in the preceding section on the theoretical underpinnings of this research and narrative analysis, the notion of one identifiable truth is rejected in the light of there being multiple realities and multiple meanings and interpretations. However, although the researcher is not seeking validity it is important, that the research is rigorous and credible, “*well grounded and supportable*” (Polkinghorne, 1988,p.175). As stated by Mishler (1990, p. 420) “*focusing on trustworthiness rather than truth displaces validation from its traditional location in a presumably objective, non-reactive, and neutral reality and moves it to the social world- a world constructed in and through our discourse, and actions, through praxis.*”

With a focus upon trustworthiness and credibility the following criteria were applied within this research.

1. Transparency. This refers to how clearly a reader is able to see the stages in the process of the research that lead to the interpretations reported (Yardley, 2008). This is incorporated within the methodology section and Appendix M, which details the stages of analysis to enable someone else to follow the process of this research. Transparency was also upheld through peer review of my interpretations by both my supervisors and fellow trainees using narrative analysis for their research. This enabled feedback on the storylines reported, where they were heard, and also where other storylines were heard, enabling the researcher to reflect upon and incorporate the role of her assumptions in the reported narratives. The results include direct quotes to show the link between the narrative and the interpretations made. Finally, as results are a situated interpretation, it was important that the reader is made aware of the researcher’s position towards the research and the context in which it is

situated, which is the reason behind the introduction starting with the researcher and her position, and also for the inclusion of a reflexivity section within the methodology. It was also one of the reasons for keeping a reflective diary throughout the research process to try and remain aware of my assumptions and their role in the process and interpretations made.

2. Persuasiveness. This refers to whether the interpretation is “*reasonable and convincing*” (Riessman, 1993, p.65). Following Riessman (2008) guidance the use of quotes was used to help the reader see the association between the interpretation and the transcript. Again, peer review and feedback was used to assess if the results upheld these criteria.
3. Coherence which was referred to as “*the way different parts of the interpretation create a complete and meaningful picture*” (Lieblich, et al., 1998, p.173). The research argument should be ‘soundly argued,’ with the reader able to clearly understand the reason for the chosen methodology and the arguments for the interpretations made (Yardley, 2008). This is reflected in a section within the methodology detailing the reason for selecting narrative analysis, how it is suited to the research question, and the stages of process of analysis. In addition the use of quotes seeks to strengthen the argument or interpretations made.
4. Pragmatic Use. (Riessman, 2008). An important criterion for the research is consideration of whether this research can form the basis for others’ research and clinical practice. In the introduction, the clinical relevance of this study was clearly stated. Throughout the analysis this criterion was held in mind in consideration of the conclusions and how the narratives shared could be used to broaden understanding and inform clinical practice. A final sub-criterion was the political and ethical use of how this research could lead to social change (Riessman, 2008). This criterion leads to the responsibility to disseminate this research widely to reach both fellow professionals, researchers, the wider public and those living with epilepsy. The start of the latter will be the presentation of my results on the Epilepsy Action website with a link to further information. I hope to publish this research and present it to many audiences to fulfil this last criterion.

CHAPTER 3. ANALYSIS

This chapter will present the interpretation of the co-constructed narratives of eight individuals on the experience of living with epilepsy diagnosed in adulthood.

Participants have been given pseudonyms and other identifiable information altered to retain anonymity. The first part of the analysis is split into two sections. As discussed in the previous chapter, narratives are co-constructed in a particular time and context for a particular audience. Consequently, brief demographic information and the context in which the meeting took place is detailed first, in order to give the reader a framework within which to situate the interpretations. The next part of the analysis, drawing from Lieblich *et al*'s (1998) 'holistic content' analysis, is a 'global impression' of the interpretation of each individual's narrative. These 'global impressions' include brief quotes from the participants' transcripts to illustrate both the presence of storylines and construction of identities, as interpreted by the researcher.

The second part of the analysis considers similarities and differences in storylines across all of the participants, connecting interpretations to existing research to present epistemological narratives (Harling Stalker, 2009). Discussion will focus upon three broad umbrella plotlines. Presenting the narratives under these shared plots allows the commonalities across narratives to be highlighted to the reader whilst also allowing for consideration of the diversity of people's positions. This was felt to fit with the epistemological position of this research and the heterogeneity of experiences shared.

3.1 Introduction to participants and individual 'global impressions'

3.1.1 Katie

Introduction

Katie was 29 years old, white British, single, working full time and living in the south of England. She was first given a diagnosis of epilepsy in April 2009 and her most recent epileptic activity occurred in the month that we met. We met at her home on a Saturday afternoon. We chatted whilst Katie finished her toast and made a drink

before starting the interview. It was during this time that Katie first introduced her experience working as an assistant psychologist within neuro-rehabilitation.

‘Global impression’

Katie portrayed an identity of someone interested in her experience, which affirmed a sense of self she had always identified herself with, someone “*slightly weird*” who was interested in “*alternative experiences*”. Her narrative of epilepsy as affirming how she stories her ‘self’ is contrasted with the story she tells of her parents’, where they are depicted as experiencing the diagnosis as “*a bit of a slap in the face,*” highlighting that she is no longer “*perfect*”. She highlighted the role of her experience in her understanding when saying “*I worked in neuro fields for like, five years, and it became like normal to me*” later commenting that “*epilepsy is only a relatively minor thing.*”

Katie’s narrative portrayed a positive relationship with epilepsy that was maintained throughout through her use of an upbeat tone and theme within her stories. In addition to comments such as, “*if it’s like a trade-off between driving and having interesting things being generated out of my brain, I’d rather have that.*” Some of the ghostly audiences (Minister, 1991) of this narrative may have been the university course director or careers adviser who both advised her of all the things she wouldn’t be able to do following a diagnosis of epilepsy, or her parents, whom she spoke of as now seeing her as less able to reach levels she might have previously attained.

3.1.2 Sarah

Introduction

Sarah was a 33-year-old woman, white British and married. We met in a private room within a council library. She had diagnoses of both epilepsy and Paroxysmal Dyskinesia. Her last epileptic activity was at the end of 2009, six months prior to the interview. Although it initially seemed as if she did not know where to start her narrative, once she started talking of her frustration at the medical profession her narrative flowed with little need for prompts.

‘Global impression’

Sarah’s narrative had a storyline of someone fighting. This was communicated in her choice of stories, use of terms such as “*fight*” and “*battle*”, and her determined tone. Sarah’s narrative started with her anger at the medical profession, which she said she would always feel. She spoke of being “*passed from pillar to post*” and “*frustration, complete and utter frustration*” at the process of diagnosis and medical management. The strength of emotion and the number of stories shared suggested a ghostly audience of the medical profession, to hear her story and enact changes and perhaps the adoption of her work role as a criminal advocate, someone who fights for justice for others.

Sarah’s account portrayed an identity of someone who saw epilepsy as a battle, and she would not let it take over her life. She spoke of initially pushing herself to her limits, using “*railings to drag*” herself into work. However, whilst the narrative suggested anger at having to keep fighting, she also said generally people at work had been “*really good, probably too*” good speaking of getting “*followed around*” and “*taxis ordered for her*”, which she found “*annoying*”. This storyline in her narrative presents a dissonance between battling to be recognised to get the adaptations she needs to work, whilst also not wanting to be seen or treated differently on the basis of her epilepsy.

3.1.3 Claire

Introduction

Claire was 27 years old, white British, working full time and living in the south of England with her partner. She had her first seizure and was diagnosed with epilepsy at 18-years old. She stated that her most recent epileptic activity had been the same month as the interview took place. We met in a private room of a local library.

‘Global Impression’

Claire's narrative had a thread throughout of loss, disruption and uncertainty. Her hesitations, apologies for “*waffling*”, and starting out saying she did not think she

would have much to say, suggest that Claire's narrative of epilepsy was not regularly told. Following a question about whether she thought her feelings towards epilepsy may change over time, Claire spoke of being "*old enough to remember*" her life before epilepsy and said "*I loved my life.*" Her use of the past tense suggests that this is in contrast to her current life. Claire's narrative suggested that the onset of epilepsy led to a departure from a shared journey she and her peers were on, and that this disruption, had lead her on to different journey that people then and now "*don't really understand.*"

Claire spoke of a constant feeling of uncertainty and frustration. For example she said, "*I've ticked all the boxes*" and despite such measures she still does not know if she will have a seizure, which she says is "*really annoying*". When asked how her life might have been different if she had not developed epilepsy, she said, "*that's something I think about, [chuckles] erm, a lot*" and shared a portrayal of a "*more adventurous*" life where she might be with a different partner, speaking of wondering if her current partner is a "*comfort blanket.*" These comments construct a contrast to her audience between self with epilepsy and self without, the latter it felt being held in a higher position.

3.1.4. Vivian

Background information

Vivian was 54 years old, white British and married. At the time of our meeting, Vivian was also receiving treatment for cancer. Her most recent epileptic activity was in May 2010, prior to this, she had not experienced any epileptic activity for some time. The recurrence of seizures was associated to complications with the cancer treatment. We met at Vivian's home in her living room.

'Global Impression'

Across her narrative Vivian adopts an expert position, sharing stories where she is giving advice on how to live with epilepsy, or of others' experiences of living with epilepsy. For example, "*I said, "Look tell her, just tell her about your experience. By*

the way this is the number for the NSE.”” The performance of a pastoral expert position may have been guided by her past role as a teacher and the context of the meeting take place with a young female student. Her use of humour, reported speech and choice of sharing stories in which she adopted this expert position also seemed to work to position her own experience of living with epilepsy at a distance.

From the start of her narrative there is a strong sense of the centrality of John (Vivian’s husband) to her experience, perhaps enhanced by being informed at the start when they were sat on the sofa together that the I would only be speaking to Vivian, at which point John left the room. Vivian not only brings John physically into the narrative through directing a question to him, but also talks of him throughout, often speaking of John’s reaction and emotions before her own. For example, in hearing of the diagnosis, *“I felt so sorry for John”* and then saying she did not really remember being told but, *“I think it was a shock for John.”* Vivian also spoke of John holding part of her epilepsy experience, the seizures, which eludes her. She said, *“he’s the only person that can talk about how I’m moving or what I look like,” ‘a lot of which is news to me.”* This gave the researcher a portrayal of a shared journey, which could not be narrated with a sole focus upon her in isolation but only relationally, with her and John as the central characters within it and often with John as the one most foremost in her narrative.

3.1.5. Melanie

Background information

Melanie was 30 years old, white British and living with her partner in the Midlands. Melanie had her first seizure at 26-years-old and stated that she experienced seizure activity most days. When asked at what age she was diagnosed Melanie said *“first at 26 briefly, then told it wasn’t epilepsy then again properly at 29.”* Melanie had a diagnosis of refractory temporal lobe epilepsy with partial complex and generalised seizures and ictal dysphasia. We met at Melanie’s flat conducting the interview in her living room.

‘Global impression’

Melanie's narrative spoke of a four-year “rollercoaster” journey to get a diagnosis of epilepsy - a diagnosis she talks of as “*taking the fun out of everything.*” The strength of this emotion is expressed in her use of metaphor: “*it's like having your legs chopped off.*” She starts and ends the story of her journey to getting a diagnosis with the time it has taken, “*four years of not knowing.*” Her narrative is full of stories of not being believed by the medical profession, in one instance of being told she could “*turn it on or off.*” I recall feeling relief when she spoke of the first doctor who believed her and was going to help: and then he left the practice and the ride plummeted again. At one point in the narrative Melanie said, “*maybe I'm dramatising it all*”, perhaps communicating a fear that in this context, of sharing her story with an NHS employee, she might not be believed again. Her detailed narrative of the impact of living with epilepsy works to counter potential anticipated accusations of disbelief—as if needing to prove that she cannot “*turn it on and off.*”

Melanie described her frustration at health professionals. For example in the repeated requests to give her history: “*it's really hard trying to, you know, hash it all up and, kind of, put it in order because I struggle with remembering things.*” There was an anger and frustration across these stories and then a change in tone to relief and gratitude when she saw the doctor who reassured her that they would keep asking her in until they understood what was happening. She said, “*I thought, God, I've found somebody who actually cares, you know, they're going to find out.*” Yet even with this reassurance she speaks of wanting to have a seizure in the hospital as physical proof. The relief of getting her diagnosis the day after she had a seizure in hospital was a palpable endpoint in this story.

3.1.6. Martin

Background information

Martin was 52 years old, single, and described himself as white Roman Catholic. Martin was 42 years old when he had his first seizure and received a diagnosis of

temporal lobe epilepsy. When we met it had been 7 months since he had experienced seizure activity. We met in a private room of a university library in the north of England.

‘Global Impression’

Martin’s narrative began with the onset of his seizures, which he spoke of as being due to “*the shock*” of his father’s death and his burial three days before the first seizure. Martin’s narrative portrayed an active search to find a cause for the seizures and understand his epilepsy. This was conveyed through his inquisitive tone, stories in which he tried to link a seizure to an antecedent, and in his use of language, ending many of his exchanges with questions that sought confirmation of what he had just said or further information to guide his search. For example, following a story about a seizure he says, “*Could it have been from a few late nights?*” Yet alongside curiosity there is distance, feeling disconnected from the experience due to not knowing what he does or how he looks during seizures, speaking of “*how it’s like talking about someone else.*”

Martin says throughout his narrative that he is “*fortunate.*” These stories appear to position Martin at a distance from epilepsy, which he refers to as “*frightening*” and which may lead him to be seen “*differently.*” This feeling is further reflected as he questions if, and how he would tell a new friend he has epilepsy: “*would you tell, you know, how do you tell them?*” suggesting he has never done this in the 10 years he has lived with epilepsy. At two points in his account Martin refers to historical treatment of epilepsy, saying, “*you know, people used to get locked up*” and how people used “*to get put in these centres.*” He speaks of how much knowledge has moved on; however, his narrative suggests perhaps he positions himself as “*fortunate*” to create distance from those narratives of people who were “*locked away.*”

3.1.7 Emma

Background information

Emma was 48 years old, white British, single and Jewish. She had her first seizure at age 34 and was diagnosed with epilepsy at age 35. Her most recent epileptic activity

was the week before she completed the background information sheet. We met in a private room of a library in the north of England. Before the interview started she mentioned some of the work she had done developing understanding of epilepsy for those living with it and the medical profession.

‘Global Impression’

Emma’s narrative of living with epilepsy moved from stories of “*business as usual*” following her diagnosis, through various turning points to her current position following becoming single, in which she talked of having “*fears about injuries and not being able to get help*” and how these were “*in the back of my mind all the time.*” Although she spoke of her original position being “*business as usual*”, comments that “*nothing really changed on the surface*” and following joining an epilepsy online forum she didn’t feel “*so isolated*” indicate the presence of another story of her initial experience not shared in this context, perhaps as it did not fit with the identity she wanted to portray.

The part of her narrative that Emma said was “*quite hard for me to talk about actually [chuckles]*” and in which she was emotional sharing, was the change in the experience following becoming single. It is in this context that she presented difficulties talking about her status: “*I mean, when do you tell somebody when you, you know, when you start dating, just when do you tell them that you’ve got a disability?*” From stories which portrayed a sense of independence, she moved to stories of concern that there was not a partner there. Her narrative contained a dissonance in not wanting to use the word ‘carer’ for past partners, suggesting she still does not position herself as someone in need of care, but also speaking of needing someone there. Similar ambivalence, related to her illness status, is seen in the way that she at times aligns herself with being ‘disabled’, to access support such as seats on a bus, whilst at other times she moves away from this position and says she doesn’t look disabled, and uses her position to enable her to adopt the identity of a crusader fighting for others’ ‘disabled’ rights.

3.1.8 Richard

Background information

Richard was 77 years old, married and described himself as a Methodist white West Indian. He had his first seizure and stated he was diagnosed with tonic clonic seizures at age 75. His most recent epileptic activity was seven months prior to the interview. We met in a private room at a university in the south of England.

‘Global Impression’

Richard’s story began with repeated statements about “*feeling inadequate*”. This repetition indicated both the strength with which this narrative is held and the importance that it was heard. This statement of feeling inadequate sets up a contrast of a preferred identity. It sounded as if it was important for him to set up this contrast from the beginning and to share the stories of when he was ‘adequate’ to portray an identity that he has not always been this person with epilepsy who depended on others; he was someone others depended on. It also suggests someone struggling to maintain his narrative of self with this narrative of self with epilepsy.

Richard’s narrative worked to communicate an underlying stoicism, through his use of tone, humour, and statements such as “*I’m lucky compared to most people*” or “*you’ve got to be determined*”, portraying an identity of someone that won’t let epilepsy beat him. However, he commented within the meeting that his experiences were hard to talk about. Such comments suggest an alternative story that may have been difficult to tell perhaps due to the difference in my gender and age and the context of this being a research interview impacting upon the narrative co-constructed. Richard also spoke about the historical treatment and narratives of epilepsy. He spoke of how “*the general reaction, I think, perhaps a couple of decades ago, would have been horror, and you know, we must keep away*”, positioning this in the past. However, his reluctance to talk about his epilepsy suggests he still expects others to hold a stigmatising narrative of “*this horrible disease.*”

3.2 Similarities and Differences

Following individual analysis, the narratives were considered collectively focusing upon both the content and how the stories were performed. In reading and analysing the narratives it became evident there were three broad plots referred to in each narrative, as displayed in Table 2 (on the following page). The narratives are presented as a collective, not to “*create yet another “general unifying view”*”, but “*to encourage closer attention to the stories*” and so “*aid listening*” (Frank, 1995, p. 76). Narratives are co-constructed and situated in a specific context; as such positions are seen not as static but dynamic. Within shared plots different positions are considered so as to highlight diversity in experience.

The plots are not positioned temporally as participant’s narratives- (as other narrative researchers have reported)- did not follow the clear temporal order that is sometimes expected by Western researchers (Elliot, 2005; Riessman, 1993). The chosen presentation was felt to match with the participants’ narratives, which spoke of experiences over time but did not present their narrative in a clear temporal order. The structure of the accounts may be shaped by the interview guide that did not ask about experience in a chronological order, as a life history approach (McAdams, 1993) would advocate, but by topics, hence people’s narratives are topic- centred (Riessman, 1993) rather than in a chronological sequence.

Considering the similarities and diversities across narratives in relation to these plots enabled an additional level of analysis, deepening the understanding of the narratives of living with epilepsy in adulthood as a collective as opposed to individual experience. Plots and storylines are also considered in relation to existing literature and dominant narratives of living with epilepsy and chronic illness, presenting ‘epistemological narratives’ of the researchers’ interpretations (Harling Stalker, 2009). The three shared plots to be considered in turn are: stories of onset, stories of changes, and the meanings of epilepsy.

Table 2: Shared Plots and Storylines

<u>Shared Plots</u>	<u>Storylines</u>
<u>3.2.1 Stories of Onset of epilepsy</u>	<p>‘Affirmation’ of stories of self</p> <p>‘Flow’ and continuation of stories of self</p> <p>Biographical Disruption to stories of self</p> <p style="padding-left: 40px;">Disruption to life and family stages</p> <p style="padding-left: 40px;">Disruption to future biography</p> <p>Searching for cause, searching for a meaning?</p>
<u>3.2.2 Living with epilepsy: stories of changes and challenges</u>	<p>Dependency</p> <p>Emotional expression</p> <p><i>“I try to think positively”</i></p> <p><i>“It’s like talking about someone else”</i></p>
<u>3.2.3 Stories of meanings of epilepsy</u>	<p>Something ‘normal’</p> <p>Something <i>“all a bit scary”</i></p> <p>Something others may be scared of</p> <p>Something people used to get <i>“locked up for”</i></p> <p>A ‘hidden’ illness</p> <p>Family Narratives- ‘it’s not to be spoken about’</p>

3.2.1 Stories of onset

Introduction

The way the onset of epilepsy was told varied across participants. All of the interviews started with the same question, whereby participants were asked to share their experience of living with epilepsy. Seven of the participants started their narratives with their onset of epilepsy; one of these was following a prompt question from the researcher. The beginning of a narrative with the onset of epilepsy may be guided by the Western culturally accepted understanding that a story has a beginning, middle and end (Riessman, 1993); as such the onset may seem a natural start. In contrast to the other participants Vivian, did not start her account with the onset. Following the initial open question she asked what was meant by living with epilepsy and following a prompt on any possible changes or impacts of her epilepsy she commented that she may be “*knocked out*” for a day after a seizure, but how she is “*very lucky*”, as until recently she had not had many seizures so, “*in terms of having a big impact, it hasn’t particularly*”, setting up a position taken throughout her narrative which appeared to place distance between her and the epilepsy. This is a position which is discussed in relation to her stories of onset.

In relation to the onset, in keeping with Scambler & Hopkin’s (1986) community study of epilepsy, participants accounts suggested a general sentiment of shock and hearing of what had happened through others. For example, Sarah spoke of the onset of epilepsy “*coming completely out of the blue*” and of coming around to see faces of paramedics. Katie spoke of waking up to find “*there was lots of people sort of standing around my bed.*” Melanie spoke of waking and her friend telling her, “*you had a seizure in your sleep*” and I went, “*no I didn’t*” her use of reported speech and intonation indicating the sense of surprise. However, although the onset was sudden for all, the way the onset of epilepsy was told varied. Those whose narratives were most strongly characterised by themes of ‘disruption’ seemed to share most stories of searching for or naming a cause, as if trying to find a meaningful place for epilepsy in their life, as suggested by Williams’ (1984) concept of ‘narrative reconstruction’. In contrast, in narratives that suggested a sense of ‘reinforcement’ (Carricaburu &

Pierret, 1995) or ‘flow’ (Faircloth *et al.*, 2004) following onset the search for meaning appeared to be absent. The storylines of onset represent a continuum from a story with a theme of affirmation, to ones of continuity and then of disruption. This presentation displays the varying impact onset may have and the role of context upon the story told.

‘Affirmation’ of stories of self

For one participant, the onset of epilepsy was positioned at that time as something that has added to her life and understanding of self. Katie said, “*so...you know, I’m fairly sure that it’s been going on for about 15 years, and that those sorts of things...that I’ve always just put down to being slightly weird elements of my personality, were just the complex partial seizures. So, it’s been quite interesting to find out more about it.*” Later on, following a story about her experience of déjà vu’s, she commented that, “*it would be pretty boring if you kind of exercised it from my brain.*” This suggests an active curiosity about her epilepsy and interest in it allowing her to see things from what Katie referred to as “*a totally different perspective.*” The narrative constructed in that context suggested that for her the onset of epilepsy did not challenge taken-for-granted assumptions or explanatory systems, two of the criteria suggested for biographical disruption (Bury, 1982). Instead it had a sense of ‘biographical reinforcement’ (Carricaburu & Pierret, 1995) or affirmation in the sense it “*corroborated something*” and “*validated*” her intuitions (Stevens & Doerr, 1997, p. 530) enabling her to create links with the past.

‘Flow’ and continuation of stories of self

Emma spoke of “*not batting an eyelid*” at her diagnosis saying, “*I just thought okay, it’s happened to me.*” For her this was perhaps within the context of two members of her immediate family having epilepsy that had been in remission for some time. Hence it could be argued, that for her onset did not challenge explanatory systems: she had an illness narrative for epilepsy, acquired through her family which perhaps positioned it as something that can be lived with. This could account for the progression of a narrative ‘flow’ (Faircloth *et al.*, 2004).

Vivian's account, in contrast to Emma, and fitting with her positioning throughout the interview appeared to distance self from the onset. Vivian was the only participant not to talk about onset at the start of her narrative. She gave few details of onset and diagnosis only commenting, following a question about the onset, that she came to "*looking into the eyes of a very dishy doctor and it was lovely.*" Such a comment was interpreted to work to normalise the experience and distance Vivian from stigmatising narratives of epilepsy, consistent with her position adopted throughout the narrative (Harré & Van Langenhove, 1999). Her storyline of onset it is argued displays continuity in the narrative performance and consistent portrayal of a preferred identity in which the epilepsy is distanced.

Biographical disruption

In contrast to the above narratives, Melanie, Richard and Claire's accounts of onset suggested a 'biographical disruption' (Bury, 1982). Melanie began her narrative by contrasting her current life to her life pre-epilepsy. She said, "*so from having a very active and a bit mad life sometimes from, you know, late teens up to being mid twenties, having that just taken away from you is just awful.*" She spoke of the disruption and loss to the extent of looking in the mirror and thinking "*I don't know that person*" and feeling as if she had had her "*legs chopped off.*" A metaphor which also communicates her perceived increased reliance on others. The disruption to Claire's life following onset also dominated the early part of her narrative, referring to onset as seeming "*like the end of the world.*" For Claire it was perhaps the social comparison that made her disruption so pronounced (Singer, 1974). She associated her experience of disruption to "*cultural stereotypes*" held by others of herself as a student, a teenager and someone Irish, for which she encountered expectations that she would always be keen to drink alcohol, and the conflict between these expectations and being someone living with epilepsy who needs to be careful with alcohol. For Richard it was being informed he would lose his driving licence, when given his diagnosis, that the disruption of epilepsy "*hit him.*" The disruption to Richard's life seemed to centre upon his loss of independence and a sense of "*inadequacy,*" a story that seems in contrast to stories of self pre-epilepsy. He spoke of the onset of epilepsy

bringing changes which he found “*difficult*” and which “*people who don’t know*” him “*would not know, and would not see*” but said “*there has been a change*” suggesting a felt disruption not only to practical daily life but also to stories of self.

In contrast, to the above stories of disruption, Sarah spoke of fighting the epilepsy, dragging herself into work and almost not accepting the disruption. She spoke of being “*told I shouldn’t have a bath, shouldn’t be on my own, shouldn’t be leaving the house because it was so frequent, umm, and I refused to do that.*” Sarah spoke of the disruption to her career and her “*mourning*” for this. Her stories of battles to get the adaptations she needed at work implicitly tell of the disruption of epilepsy. However, her narrative construction and performance work to minimise the disruption, perhaps to distance herself from someone struggling. Sarah’s epilepsy may have been just as disruptive on a practical level, but this was not heard, indicating the role of agenda and performance in narratives.

Within this storyline of biographical disruption, two further storylines are considered: stories of disruption to life and family stages and stories of disruption to future biography.

Disruption to life and family stages

The onset of illness has been described as a non-normative life event:- in contrast to stages such as leaving school or menopause, it is not an anticipated event and hence can cause particular disruption to family systems and roles (Atwood & Weinstein, 2010). Some of the participants’ narratives spoke of the onset of epilepsy as causing a disruption in life stages and the family life cycle and roles. For example, Claire told that “*mum thought it would be a good idea [chuckles] for us to sleep in the same room, and then dad to sleep in a separate room, which when you’re 19 is kinda like, I don’t really want to sleep in the same room as my mum!*” her use of humour perhaps indicating a discomfort and embarrassment in this situation. She then went on to tell of how her mother then decided to put a baby monitor in her room to hear if she had a seizure in the night, “*... something as well you didn’t really want to erm, you didn’t really want to tell your friends about. Erm...sorry. [sniffles and starts to cry]*” She

repeatedly mentions her age, suggesting this is significant to her. This is contextualised by the disruption to life-stage plans that Claire talks of: rather than travelling the world as planned or going to university like her friends, she is at home sharing a room with her mother. Sander's *et al* (2002) spoke of illness in older adults as sometimes being an 'anticipated event', the contrast to this is evident in Claire's experience, as an eighteen-year-old, this was an unanticipated event perhaps enhancing the biographical disruption to both her and her family.

Melanie and Katie's experiences also suggest a change to anticipated family cycle. Both participants spoke of moving back home after a period of independent living so that parents could care for them. These stories suggest a disruption to the 'normal' trajectory of the family life cycle (Carter & McGoldrick, 1999) which may be challenging for both the individual and the family. They highlight the disruption of illness onset being not just to the individual, but reverberating through the systems that participants were part of (Chamberlayne & King, 1997; Richardson, Ong, & Sim, 2006).

Disruption to future biography

The participants' narratives also raised the position of future disruption or losses, positioning biographical disruption as something that can be experienced across the journey of illness, not just at onset but whenever there may be a disruption to anticipated biography for the individual or the family (Becker, 1997). Bury (1982, p. 171) spoke of this as a "*biographical shift from a perceived normal trajectory through relatively predictable chronological steps*" to one that diverges from the expected. One such future change, which was spoken about by two participants, (both young women) was the decision of whether to have children. Claire said, "*as I get older you think*" about children and "*not knowing the ins and outs of it but wondering, "Am I, am I gonna do that at some point? Am I not?" I don't know*" Similar uncertainty comes into Sarah's account, as she spoke of how she and her husband had talked about whether in the future they might get her husband's vasectomy reversed, but when her seizures were frequent, decided not to. Sarah attributed this decision to,

“knowing about the effects that it has with the drugs, I just thought it’s too much risk.”

Research suggests this decision is one commonly faced by women with epilepsy, with a survey finding that a third of women were considering not having children due to their epilepsy (Crawford & Hudson, 2003). Claire and Sarah’s storylines provide one example of how onset may not just cause disruption to current biography, but potentially to future stories of self, a finding also suggested by Travers & Lawlers’ (2008) study of the onset of Chronic Fatigue Syndrome. In this example, disruption may also extend to gendered identities and what it means to be a woman in a society in which motherhood maybe dominantly associated with narratives of being a woman (Riessman, 2000).

Searching for a cause, searching for a meaning?

Martin, Melanie, Richard and Claire all spoke of searching for a cause for the onset of epilepsy. This may be to maintain a sense of continuity and meaning with the cause providing a platform, as suggested by Hyden (1995), upon which to *“locate the illness...in their map of the world”* (Stern, Doolan, Staples, Szmukler, & EislerI, 1999, p. 5). Janoff-Bulman’s (1992) Shattered Assumptions theory suggests that onset of an unexpected disruptive event, such as epilepsy, may challenge held assumptions about the world as a meaningful and safe place and the self as healthy. This may lead to the need to find a cause and meaning to enable the development of narrative that flows across time and perhaps *“reconstruct a sense of order from the fragmentation”* produced by onset (Williams, 1984, p. 177). This search for a cause seemed to be most present in participants accounts that had stories of ‘disruption’, in contrast with those of that spoke of ‘affirmation’ or ‘flow’.

For Martin and Claire this storyline of searching for a cause was present throughout their narratives. Richard spoke of his first reaction as being *“why has it happened to me?”* telling of how he had then begun reading journals and literature on epilepsy to help him understand perhaps to develop a sense of order and control (Kleinman, 1988). Martin started his narrative with an account of the shock of onset, and then straight after his conclusion, *“I just, I honestly think it was the shock”* of his dad’s death and the burial, which had been three days prior to his first seizure. He later

returned to this mid-way through his narrative, again commenting, “*The interesting thing, why did it come on though? I honestly think it was the shock*” ... “*Maybe I’m a bit soft as well, but, erm, I honestly think mine it must have been the shock.*” The unprompted reiteration of this message suggests the importance for Martin of naming a cause perhaps to help to understand his experience.

Both Melanie and Claire, whose narratives contained stories throughout of disruption, associated onset within their narratives with their active lifestyles and working hard. Melanie commented that, “*I had a really, really busy hectic life, so I think a lot of people thought, you know, it’s your body’s way, even I thought it was my body’s way of saying, you know, just pack it in.*” She commented that she didn’t think anybody was “*overly shocked*”, given her lifestyle and the hours she worked. Claire also spoke of the onset being due to “*living it large,*” referring to working long hours. Melanie and Claire’s narratives both appear to construct narratives of causation for the onset, which suggest an internal locus of control (Rotter, 1954). This gives onset some certainty and control, which was also found within Raty *et al’s* study (2009) of people’s experiences of epilepsy. Claire said, “*things are easier, I think, to kind of accept whenever it’s your, it’s your fault or you, not your fault, but you kind of attribute what the reason.*” For Claire and Martin this need to find a cause was still dominant years after the onset, with Claire commenting she is the type of person that likes to know why things happen, and part of her struggle with epilepsy was the uncertainty. She said, “*I still, because I don’t understand why and because you know, what, just why generally, why, you know, why, why generally, because there’s no, ‘okay, well you had, you know, a car accident and you hurt your head,’ or whatever, there’s, there’s no, er, reason like that.*” This suggests that perhaps epilepsy and its inherent uncertainty challenged held narratives that events are understandable. This challenge seemed present in Claire’s struggle and Martin’s active search to understand, evident in his use of ending many of his exchanges with questions. In contrast, Sarah’s narrative told of fighting to find a medical treatment, not needing to know the cause. She spoke of just wanting “*it to be controlled.*” In keeping with the ‘fight’ communicated through her use of tone, pace and vocabulary, she did not

present herself as needing to find a cause, only a treatment to regain control and not let epilepsy take over.

In contrast to Melanie, Martin and Claire, Emma and Katie's narratives contained no searches for a meaning. For Emma, epilepsy was a known entity. She spoke of telling her doctor when informed she may have had an epileptic seizure: "*I said straight away, "well, it probably was because it actually runs [chuckles] in my family."*" Katie's narrative also did not include stories of searching for a cause; she spoke of epilepsy as affirming how she saw herself and stories past experiences. She contrasts this with her parents who are described as holding a different story that did not 'fit' with narratives of epilepsy, and of them having an ongoing search for a cause. Katie spoke of how they queried if a malaria tablet she had taken had caused the onset saying, "*they still want to kind of, blame it on some external thing.*" Vivian's story also does not contain stories of disruption following onset, and there is no search for a cause. She commented when asked about the diagnosis that she was "*happy there was an explanation.*" This position may be guided by her context of living with two illnesses (cancer and epilepsy) both of which she has seen move between active and passive presences in her daily life, one of which, cancer, had recently returned without an explanation.

3.2.2 Living with epilepsy: stories of changes and challenges

Introduction

Unsurprisingly, participants' narratives shared stories of the changes and challenges of living with epilepsy. The changes spoken about and the way in which the stories were told are compared and discussed under the storylines of: dependency; emotional expression; "*I try to think positively*" and "*it's like it's happening to someone else.*"

It is notable that Martin's narrative is mostly absent within this section. He repeatedly positioned himself as "*fortunate*" (fourteen times) in his narrative, and this worked to limit consideration of stories of change or where he was not "*fortunate*". This is considered further in the next section on meanings of epilepsy.

Dependency

A storyline present in four of the participants' accounts was a change to an increased dependence on others. For example, Melanie spoke of not being able to have a bath alone, tentatively using the word "*demoralising*" to describe this position. She speaks of how she could cope with "*the restrictions*" it puts on her, but hating "*what it does to my partner, what it does to my family.*" It is this importance of the presence of others for safety and care that led to a turning point in Emma's narrative of living with epilepsy from it playing a minor role and her comment of "*business as usual*", to thinking about her safety and risk of injury regularly. It is also part of her experience that she spoke of finding it "*quite hard*" to talk about, indicating that perhaps this dependence on others does not fit with other stories of self. Sarah also refers to the impact of epilepsy upon independence; however, in keeping with her fighting position, she speaks of her battles to get adaptations she needed at work to maintain her independence, and her annoyance at people being "*protective*", suggesting positioning to distance self from someone dependent on others.

Richard refers to this change in independence within his narrative when he speaks of his son coming to stay whilst his wife was away. Richard speaks of acknowledging the reasons for this on a practical level, but on another level perhaps struggling to relate this situation to himself, saying, "*the logic of that was he could drive, use the car and drive me in, but thinking, 'I'm not allowed to be on my own,' you know, 'Am I that bad? Am I really that ill?'*" His narrative suggested a difficulty with what may be a role reversal of depending on someone who perhaps he is used to having depending on him. For him it seems it is this very dependence on others which he sees as a major change and challenge to his narrative of self, evident in his questioning, "*am I really that bad?*" It is change that moves him to what he stories as "*inadequate.*"

Bury (1982, p. 177) spoke of this dependency in illness as disrupting "*the normal rules of reciprocity*" which may lead one to feel a sense of being a burden and which discredits the self (Charmaz, 1983). Travers & Lawler (2008) spoke of the guilt in not

being able to fulfil roles. This sentiment is heard within this research in Richard's narrative, saying, "...generally feel that I'm...you know, dependent on other people too much." This sentiment was also heard within Melanie's narrative when she speaks of how friends say, "I'll give you a lift home and I'll wait with you until Paul gets home", and feeling that, "they shouldn't have to do that...you know, I should be able to do that by myself." Such experiences highlight the challenges of living with epilepsy in the experience of it taking away part of your independence, leaving some people with a sense of dependence.

The sense of dependency may be associated to changes in relationship roles. Byng-Hall (1995) spoke of how illness can challenge the roles adopted within families or relationships, for example challenging counterpart roles such as "*she cares, he provides*" (Byng-Hall, 1995, p. 267). This is suggested in Richard's narrative of struggling to have his son care for him and his wife drive him to places, a role which perhaps has usually had the opposite dynamic. This may challenge stories of self, causing a shift in which self with epilepsy is in the foreground (Paterson, 2001).

Emotional expression

The varying impact of changes being related to dominant gendered and generational societal narratives was suggested in the different ways Katie and Richard spoke about having less control over their emotions, due to side effects of medication and location of seizure activity. Katie (a 29-year-old woman) spoke of being more open and emotional with friends, and Richard (a 77-year-old man) spoke of getting more emotional watching TV shows or when with his family. However, the individual's position in relation to this change varied. Katie spoke of this change as positive, bringing her closer to her friends. Katie spoke of friends commenting, "*it's really nice that you tell us, you know, like you're disclosing more things about how you feel*", saying how she would like to "*retain a bit of that now*" as it's "*quite nice*". Whereas Richard found this increased emotion almost embarrassing. He stated, "*even with watching a television programme, I can feel I'm starting to cry on it, and I find this difficult.*" Buruck & Daniel (1995) argued that gendered narratives are one of the

central storylines people draw from when making sense and constructing a narrative. I wondered if Richards' struggle was partly due to the change not fitting with dominant western gendered narratives of men, which may be stronger in older generations, that emotions should be concealed and expression is seen a weakness (Seider, 2007). This may have been heightened by the context of telling his narrative to a younger female. On the other hand for Katie, as a young woman, the more dominant narratives are of the acceptability and almost the expectation of women to openly express emotions; hence her change fitted with the dominant narratives. Katie's position may also be associated with her experience of working as a psychologist, which may have made expression of emotions more normalised. These differences, support previous studies, which indicate the role of gendered narratives and context upon experiences and understanding of illness (Bendelow, 1993; Stern, et al., 1999).

"I try to think positively"

Across narratives participants spoke about positive sides of epilepsy in relation to being "*more healthy*" (Richard), how epilepsy had "*enriched*" (Emma) their life, "*having more positive characteristics*" (Sarah) and being more "*in tune*" (Claire) with their bodies. Such comments agree with studies of other illnesses that have suggested illness can bring gains and new insights (Asbring, 2001; Carel, 2007; Whitehead, 2006). However, positive comments may work to present a restitution narrative. For example, Marin spoke of how "*half the battle is being positive.*" Melanie spoke of, how, now four years on epilepsy is, "*not so much of a demon any more, it's just there, it's learning to live with it alongside rather than letting it control and run my life now.*" Such comments and the suggestions of positive change over time work to position the story within a restitution narrative (Frank, 1995). It is striking that even Melanie's narrative, which contains many stories of loss and speaks of "*hating it*", contains the phrase, "*I try to think positively*", as if this is what is expected and what should be told. The restitution narrative is seen to be more culturally accepted (Smith & Sparks, 2008) and portrays the person in a more positive light as being 'successfully ill' (Frank, 1997, p. 117). This may have particular impact in the wider context of an NHS system in which a 'struggling' or a 'chaotic' narrative may lead to

difficulties with seeking care, as suggested by Melanie's account in which she associated her difficulties sharing her experiences to the doctor's comment that she could "*turn it on and off.*" This suggests that for some participants the context of the meeting taking place with an NHS employee and the societal dominant narratives of 'acceptable' stories may have impacted upon the narratives co-constructed.

"It's like talking about someone else"

An aspect of living with epilepsy that several participants spoke about was that they do not know what happens to them during their seizures. For example, Martin twice mentioned that "*it's like talking about someone else*" spoken with an almost curious tone. Both Vivian and Melanie referred to the fact that their partners go with them to medical appointments to share what the seizures look like. Vivian commented that, her husband, John's "*the only person that can talk about how I'm moving or what I look like and so on and so on. A lot of which is news to me.*" This break from knowledge about the self is in contrast to what we normally experience, in which we are the main author of our bodily experience; although it may be described or formulated in different ways by others. This is something which it seems is taken away, or hidden, by epilepsy. Mattingly (1998) stated it is through the body that we gain a sense of order, however, the experiences of people with epilepsy contrasts this suggesting they have to gain a sense of order or understanding of what has happened through others. For some, this elusive aspect of their epilepsy may also be associated to a sense of embarrassment through the explicit loss of control. Vivian spoke of how you "*couldn't stop yourself doing them and in hindsight a flashback over the next few months, you suddenly see yourself having done it and can be, kind of, embarrassing.*" Stating how "*the postman definitely got more than he expected to see once*" due to a sense of confusion following a seizure. Although this was said with a humorous tone, it is in contrast to the well-put together appearance and performed identity shared in our meeting. Such experiences indicate some of the difficulties of living with epilepsy, in that a central part of the experience is always out of your control and has to be narrated by another.

3.2.3 Stories of epilepsy and its meanings

Introduction

Interwoven in all of the participants' narratives were stories about how they understood epilepsy and how they spoke about this with others. Bury (1991) spoke of the degree of biographical disruption in relation to the meaning in reference to the consequences, but also the significance of the illness, the fact that "*different conditions carry with them different connotations and imagery*" (p.453). The participants' narratives suggest it is the latter that has most impact upon their narratives and social management of epilepsy.

Narratives and the meanings of epilepsy are influenced by the societal context. The current societal context and legislation places value on attributes such as being healthy and employed, which are outside of the grasp of some people with epilepsy. This may lead to felt alignment with stigmatising narratives or the feeling of holding less social value (Reidpath, Chen, Gifford, & Allotey, 2005). This is highlighted by Scambler (2004) in the broadening of his concept of felt stigma from the individual focus to a wider sociological focus. As cited in Fernandes *et al* (2011, p. 3) "*epilepsy persists as a stigmatising condition in capitalist economies whose norms of social 'worth' create a situation for shame for the chronically ill.*" This position advocates the role of the consideration of societal values and legislation in the experience of living with epilepsy; something that is not explicitly spoken about but is implicitly part of participant's experiences.

In all of the participants' accounts, there was reference to wider societal, family or cultural meanings of epilepsy. The following section will consider the different narratives of epilepsy spoken about, and how these appeared to relate to the participants experience and their own understanding of epilepsy. The first storyline of something 'normal' presents a 'counter-narrative' (Bamberg & Andrews, 2004) to the other storylines that all have a meaning connected to the 'stigma' of epilepsy. However, although they are all connected to the social meanings of epilepsy, they are presented individually to highlight the different ways in which this meaning was spoken about and how it reverberates across different systems and relationships.

Something 'normal'

Katie, perhaps in the context of her work experience, appeared to understand epilepsy as a medical condition, something that had a known medical meaning and was 'normal'. She spoke of knowing "*how complex the brain is*" and how following her experience working in neuro-rehabilitation "*it all became like normal.*" This medical meaning of epilepsy was also found to be a meaning held by participants in Raty *et al's* (2009) exploration of people with epilepsy's understanding of the illness. For Katie epilepsy, at that point in time, was spoken about as something "*interesting*", which may be represented in her statement of telling everyone "'guess what? I've got epilepsy'", expressed with a tone of enthusiasm. Katie's position presents a 'counter-narrative' which challenges dominant narratives of stigma and concealment (Bamberg & Andrews, 2004). However, she also spoke of how this position might have been different if she had been told when she was younger, a storyline also heard within Martin's narrative. Katie spoke of how "*it would have been more of a bigger issue*" when younger, which she related to how older people might know more and so be "*a bit more understanding.*" Whereas Martin related this to the belief that epilepsy would have more of an impact upon your social life if you were younger. He stated, "*it'd be worse if I was a young lad and couldn't go out drinking.*" This indicates the role of life stages and the associated narratives one may be drawing from upon meanings of epilepsy.

Something "*all a bit scary*"

Katie's understanding is in contrast to the way Claire spoke about epilepsy as something embarrassing and "*all a bit scary.*" Claire set the context of this by starting her narrative with a story of her first experience of being near to someone at school having a seizure, and how she was "*too scared to look around.*" This is a meaning of epilepsy that she appears to continue to carry, and which is reflected in her decisions as to who she tells about her epilepsy. This experience supports Kilnic & Cambell's (2009, p. 665) finding that "*negative misconceptions of epilepsy and seizures prior to diagnosis have also been identified as contributory to felt stigma.*" It is such narratives

that appear to lead individuals to conceal their condition. As stated by Scambler & Hopkins (1986, p. 38) following their study of experiences of living with epilepsy, *“the fear of enacted stigma leads to a policy of non-disclosure, a policy that remains feasible for as long as they are “discreditable” rather than “discredited”*. For Claire epilepsy was something she concealed, saying, *“I don’t tell many people unless they need to know,”* perhaps as others may also find it ‘scary’. She questioned herself following a story of not telling a new friend, stating, *“why don’t I want to? I thought well, he doesn’t really need to know, A. B, I don’t really want him to know because yeah, it might change his opinion of me.”* The rhetorical work within her narrative suggests an ongoing struggle with epilepsy, a fear of risk of rejection (Schneider & Conrad, 1983) and being stigmatised due to her epilepsy, which she conceals to retain her ‘normal’ identity (Goffman, 1963).

Something others may be scared of

In contrast to Claire, who spoke both about her own fear of epilepsy and fear of others’ reactions, Vivian only spoke about others’ reactions, perhaps to retain her position and distance from self with epilepsy. Vivian said, *“they hear the word “epilepsy” and it’s like there’s a stigma or something; they expect you to go mad or all sorts of things.”* However, despite advocating the importance of talking about epilepsy, she spoke of not *“broadcasting it”* and how she *“makes no secret of it but equally it’s not a topic of conversation.”* Her narrative construction appears to work to place the negative meanings of epilepsy as being held by others, not her, and her concealment as being respectful to others as opposed to being due to felt embarrassment or shame. This was also communicated in her comment within the interview that I should not worry, *“she’s not going to throw a wobbler now”*, which I interpreted as suggesting that she would expect me to be scared if she were to have a seizure. In addition, the use of the term ‘wobbler’ suggests work to normalise her seizures and distance self from the stigma, in fitting with Good & DeVelchio Good’s (1994) study, in which the term ‘Bayilma’ or fainting was used rather than seizures, perhaps to create distance from narratives of complete loss of control and the anticipated associated anomic fear (Bagley, 1972).

Melanie spoke of the stigma of others, stating, *“I do feel that there is a stigma about it; you know, you say you’re epileptic and people’s faces change”* going onto say *“I think they get scared if they see somebody have any type of seizure.”* Melanie spoke of using humour to help her talk about her experience, and as a way to help others feel more able to talk about the epilepsy and prevent the look of pity she spoke of experiencing seeing in others’ faces, suggesting she also felt it was something others may be scared of. Melanie spoke of telling people on *“a need to know basis”*, whereas, Sarah, consistent with her fighter position, spoke of being *“very out about it.”* This phrase draws from the ‘coming out genre’ (Squire, 1999), and is associated with homosexuals being open about their sexuality, which implicitly implies there might be something that others hold a narrative should be hidden, although this position is not stated, indicating a possible alternative storyline not performed in this context. On the other hand Emma’s narrative explicitly stated she did not hide it, saying, *“it’s part of me”* but also shared situations in which she did not tell people, for example, an employer, suggesting the complexities of negotiating the social identity of someone with epilepsy.

Something people used *‘to get locked up for’*

Richard spoke of being embarrassed by his epilepsy, telling people *“for medical reasons I’m not allowed to drive”*, but not naming epilepsy. He spoke of not talking about it for the first year, but then stated that he had started to tell more people after reading about the importance of educating others to reduce stigma and said that *“90% of people had been supportive”*, suggesting, as found within Scambler & Hopkins (1986), that the stigmatised narrative may be more felt rather than enacted. Richard’s position and expectation of stigma may have been in the context of living within a period when people with epilepsy were sent to colonies, something he refers to in his narrative. Richard spoke of how, *“Until 1970, if a husband or wife had epilepsy, the marriage was annulled”* – a time period during which he was married. Following this he mentioned, *“they had epilepsy colonies like they had leprosy colonies!”* spoken with an almost jovial tone, perhaps masking his feelings of discomfort. The inclusion of these facts within his narrative suggests a role within his own understanding and

management, and that the legacy of these policies lives on (Fernandez *et al*, 2011). Therefore, these are narratives his peers may be aware of, and perhaps may be associated with his initial reluctance to tell them about his epilepsy.

Martin, following a question on what he knew about epilepsy before he was diagnosed, spoke of, “*I know people used to get locked up, didn’t they, till 50 years ago, didn’t they?*” Both Richard’s and Martin’s inclusion of the historical treatment of epilepsy perhaps sets a context for their positions of there having been dominant negative narratives of epilepsy, and that people may still hold negative narratives, hence a feeling of felt stigma by association to such narratives.

Interestingly, in considering the narratives, people positioned themselves differently in relation to the narratives of stigma, indicative of how stigma is not always passively accepted, and of how stigma is a social construct that exists within power relations and social networks (Das & Addlakha, 2001; Link & Phelan, 2001). The narrative identity work enabled people to take different positions in relation to the stigmatising narratives (Riessman, 2000). For example, Martin, who worked throughout to contrast his own experience, as someone “*fortunate*” to people who had frequent seizures, to create distance and position self as more able. Martin highlighted his good fortune in terms of the ways that it enables him to align self with those without epilepsy; for example, by having seizures at night and so perhaps retain an in-group position. (Tajfel & Turner, 1986). Similarly Richard, straight after sharing information on colonies for people with epilepsy, worked to distance himself from these people saying, “*I’m fortunate not to have it to the extent that other people*” as if he never would have been a person sent away. Gregg (2011, p. 78) spoke about this in relation to a study of cervical cancer, stating that participants “*identified the behaviours that they felt were furthest from normal and highlighted their deviance from those norms.*” Participants accounts suggest the presence of such narrative work to distance self from stigmatising narratives.

A 'Hidden illness'

Epilepsy as a 'hidden' illness was spoken about by Sarah, Melanie, Claire and Martin, and implicit within the other participants' narratives. Sarah spoke of the need to get witness statements and recordings of her seizures to assist diagnosis. Melanie spoke of the frustration and experiences of being told it was all "*in her head*" and not being believed until health professionals saw physical proof on the EEG recordings. These narratives express a frustration at the hidden nature, which is at odds with the dominant medical narrative that can lead to questioning of the legitimacy of people's experiences (Bury, 1991) and presents difficulties in both the process and experience of diagnosis.

In contrast to the frustrations with the hidden nature of epilepsy, Claire and Martin position the ability to 'hide' epilepsy as positive both commenting on how they were "*fortunate*" (Martin) and "*lucky*" (Claire) to mostly have seizures in the night rather than the day, where they might be seen. For Martin, it is this hidden nature that enables him to position himself as aligned to those more able and create distance from people with active epilepsy. However, Martin also speaks of the difficulties of the hidden nature of epilepsy in relation to carrying a disabled bus pass. He spoke of how he thought bus drivers were thinking, "*what's he got one of those for?*" Emma also spoke about how she needed to use the disabled seat for her safety, but had experienced difficulties. She said, "*they look at me and I'm wearing high heels, I'm not in a wheelchair, and they're like, 'you don't look disabled'*" as she does not fit narrow societal definitions of disabled because no physical disability can be seen. Despite the Disability Discrimination Act (2005) broadening the rights of all people with disabilities the dominant narrative within society still positions disability as those that can be physically seen. This positions epilepsy, and other 'hidden' illnesses, as less 'credible' within society and can lead to invalidating responses, as described by Emma. The participants' stories suggest the complexities of living with a 'hidden' illness. Sometimes actively working to keep it 'hidden' and so retain a 'normal' self which is not 'spoilt' by the epilepsy (Goffman, 1963), and sometimes encountering

difficulties with not having the illness validated due to its hidden nature which does not fit with societies narrow definitions of disability.

In addition to the 'hidden' nature of epilepsy, one participants' account of her hallucinatory dreams suggested hidden stories of the experience of living with epilepsy. This story, although told by only one participant (Katie) felt important to be included so as not to perpetuate the 'taboo' within society that often silences expression of alternative experiences (Thornhill *et al.*, 2004). In addition to the importance and ethical use of the accounts to effect change through broadening understanding of the experience of living with epilepsy, for health professionals, people with epilepsy and the general public (Riessman, 2008).

Towards the very end of Katie's narrative when asked if there was anything about her experience of epilepsy she had not spoken about, Katie started to talk about her very vivid dreams which the doctor had told her were hypnagogic or hypnapompic hallucinations. It was of interest that she only mentioned these towards the end of her account, as if needing to feel able to speak and suggesting an initial reluctance. Her comment that she was initially not able to find anything about these experiences suggests a hiding of such experiences that maintains the mystique.

When asked about her understanding of the lack of information, Katie referred to visiting epilepsy internet blogs where others, perhaps enabled by the anonymity spoke of their experiences. She told of people saying things on the blogs such as; "*I never wanted to admit that I was hearing voices to my doctor, because I thought that he would worry that I was psychotic and "put me away".*" Katie said, "*So maybe there's, like, some degree of people not wanting to explore all that, because they're worried that that will like blend over into the more, like, into elements of like psychosis.*" Perhaps her intrigue in the "*alternative*" and experience working within neuro-rehabilitation enabled her to explore this where others may feel silenced by fear or stigma. In addition, for some people there may also be a fear of not being believed, if no information associating this experience to epilepsy can easily be found, this may be heightened if it follows a diagnostic process in which your experiences were initially not validated. Experiences, as described by Katie, are known about in epilepsy

literature (Manford & Adermann, 1998). Katie's account suggests the importance of dissemination of the possibility of such experiences by health professionals and the sharing of such experiences to dispel the mystique and normalise the experience to facilitate expression of these 'hidden' stories.

Family narratives- 'something not to be spoken about'

In addition to wider societal narratives participants also spoke about family narratives. Jacoby (2008, p. 340) in a paper on epilepsy and stigma spoke of the family home as both "*places of refuge*" and "*most hurtful stigmatisation.*" Several of the participants mentioned their families' narratives of epilepsy as something not to be spoken about. Schneider & Conrad (1980) spoke of parents as inadvertent 'stigma coaches', speaking of how if parents don't talk about it, the child learns it is something to be hidden or as something shameful (Jacoby, 2008). This research suggests that the narratives held within the family appear for some to be associated with their own meaning of epilepsy and the management of the condition, sometimes leading to repeating patterns across generations (Richardson, et al., 2006).

For Melanie and Emma, epilepsy was already present in their family, as both of their mothers had epilepsy. In Melanie's account, one of her first reactions to the diagnosis was her concern about telling her mum for fear she would feel she "*had given it to me.*" In Emma's account, she spoke of how her mum had told her "*she felt really guilty about giving epilepsy*" to her children. Within both of these families there was also a narrative of epilepsy not being spoken about, perhaps perpetuating the narrative that it is something to be hidden or stigmatised. Melanie stated that her mother "*didn't talk about it, it was something that was very, you know, you just don't talk about that, if you asked a question it was just you were told to hush.*" Emma spoke of how she spoke to her mum about her epilepsy and the possible causes but her brother, who had epilepsy when he was younger, would "*just blank her*" and "*change the subject*" if she attempted to talk about it. This is an experience Katie spoke of in relation to her parents; "*if I tried to start, like, an hour long conversation with them about having epilepsy, they would kind of... 'Mmm hmm, mmm hmm, yes...oh, erm, what shall we*

have for lunch?” Claire said that her family call epilepsy “*my problem, living with my problem*”, and that they ‘*do not like the word.*’ This suggests that perhaps the narratives of fear and stigma are sometimes held within the family, and highlights the potential effect of the family narratives upon the individuals’ accounts and management of the condition.

CHAPTER 4. CONCLUSIONS

4.1 Summary of findings

This research aimed to hear the experience of living with epilepsy diagnosed in adulthood. This section presents a summary of the findings in relation to each of the research questions.

Main Research Question

4.1.1 How do individuals living with adult diagnosed epilepsy describe their experiences?

Analysis highlighted the different ways in which onset of epilepsy was narrated and the meaning it had for participants. For some participants the way onset was told appeared to fit with the theory of biographical disruption (Bury, 1982), with narratives indicating disruption to explanatory systems and mobilising of resources. In those narratives with stories of disruption and loss, there was often a sub plot of searching for a cause and meaning for the onset, perhaps to assert a sense of control and maintain a narrative thread across time that may have been challenged by onset. However, for others there was a sense of ‘biographical reinforcement’ (Carricaburu & Pierret, 1995) or ‘flow’ (Faircloth *et al.*, 2004), a sense that onset fitted or affirmed their existing narratives. This suggests that biographical disruption should not be assumed by onset but considered as a potential hypothesis. It should be considered in relation to the immediate and wider narratives within which the person is situated in addition, as suggested by existing research, to their current and prior life experience (Cornwell, 1984; Harris, 2009; Pound *et al.*, 1998).

The analysis also suggests the importance of the consideration of context upon the narrative constructed. Participants who told many stories of loss and disruption appeared to work to position these within a restitution plot. This may be influenced by societal and cultural narratives, which lead people to construct more ‘acceptable’ narratives that align with a healthy pre-epilepsy self and distance self from stigmatising narratives. The narrative performance and the influences upon this are important considerations in understanding the accounts people tell. Such factors may

mean that an individual distances or aligns self with disruption dependent upon agenda and context, which may successfully work to lead the clinical impression of symptoms and impact of living with epilepsy to be less present than they are.

The participants' narratives suggest that the experience of living with epilepsy needs to consider the possible disruption or changes epilepsy may present at different life stages and within different systems that the person is part of, as well as the context within which one's narrative is situated. This highlights the importance of the "*social and biographical context*" in considering disruption (Richardson *et al.*, 2006, p. 1583). This research suggests that disruption or challenges may be faced across the journey of living with epilepsy, not just at onset but whenever there is the possibility of future disruption or challenges to systems one is part of, including families. At different life stages different challenges are presented, and the participants' narratives suggest this is an important consideration in understanding the impact and meaning of epilepsy to the individual and the systems they are part of. Analysis also suggested the importance of the consideration of gendered and generational narratives upon experiences and the changes people may face.

Sub questions

4.1.2 How do these narratives describe the changing individual relationship with epilepsy over time?

The participants' experiences highlight how living with epilepsy is a journey and one that may be narrated differently at different points, as well as in different contexts. Adjustment, defined as moving along a set trajectory does not fit with the experience described by the participants. Even when in remission, illness may be in the foreground due to its inherent uncertainty or the changes it presents, which challenge existing roles and narratives of self.

Participants' narratives suggest that seizure activity would impact upon the narrative constructed. However, epilepsy is more than living with the symptoms; one lives with regular reminders of changes to how the self was narrated, which can highlight disparities and cause challenges. For some participants, differences between existing

and prior roles, or having to adopt opposite roles, such as the one in need of care rather than the carer, may be the most challenging part of their journey.

4.1.3 How do individuals describe the changing relationship to self and others over time?

The participants' experiences suggest that narratives held within relationships as well as wider systems such as societal and cultural narratives, impact upon the individuals' meaning of epilepsy and their relationships with others. It impacts upon the relationship with self, in relation to what it means to have epilepsy, if this is seen as something to be hidden or to be open about, and the consequent meanings for how the self is narrated. It impacts upon relationship to others in relation to how one is perceived and narrates the self with others: for example, as someone with a stigmatised illness that should be hidden and is not spoken about. Enacted narratives which include that of legislation that may change what the person can do, such as drive, in addition to felt narratives experienced pre and post-diagnosis may lead a person to conceal their status or develop strategies of who to tell and when. The narratives suggest that decisions as to who to tell are often complex and variable, with some participants speaking of being open yet, also sharing contexts in which this position was not taken.

Some of the narratives suggest that an ability to tell people increases with time and own understanding of epilepsy. However, others suggest this is context-dependent and there will continue to be contexts, such as within families, where existing narratives of not talking about epilepsy may dominate and impact upon the individual's relationship to epilepsy and stories of self.

4.2 Implications for clinical practice

4.2.1. Dispelling the 'mystique' and building understanding

Research suggests that stigmatising narratives of epilepsy are still prominent within the wider public (Jacoby, *et al.*, 2004). The analysis supports existing research that stigmatising narratives impact upon the individuals understanding and management of the condition (Scambler & Hopkins, 1986). Scambler (2009, p. 422) spoke of how

“*stigma is an obstacle to good health and health care*”, this is also suggested in the finding that experiences of felt stigma are associated with depressed quality of life trajectories (Baker, Brooks, Buck, & Jacoby, 2000). Evidence suggests tailored psycho-educational community programs focused upon stigma can be beneficial (Reno, Fernandes, Bell, Sander, & Li, 2007). The analysis supports the importance of education and developing understanding of the condition. It is hoped the dissemination of this research will contribute towards this. However, as indicated by the analysis, stigma needs to be considered at a societal and legislative level and action is needed at these levels, or stigma will continue to be felt where difference is emphasised by distance from dominant societal values.

4.2.2 Adopting a Bio-Psycho-Social framework

Considering the person holistically

This research, in line with, the National Service Framework (NSF) for long-term conditions (DOH, 2005) advocates adopting a person-centred holistic approach to supporting people. The findings of this research support the importance of a holistic approach which incorporates any potential impact of living with a long-term condition upon the individual and the systems they are part of, widening the focus from the symptom management, as is the main focus within the NICE guidelines (2004) to adopting a bio-psycho-social framework (Engel, 1977). This recognises that “*illness is not simply an individual subjective experience; it has biological, interpersonal and social factors*” (Atwood & Gallo, 2010, p. 1). This suggests that clinicians should adopt an assessment, formulation and intervention approach that incorporates these factors to gain an understanding of the individual’s experience.

Consideration of systems

A bio-psycho-social framework would retain focus on the individual whilst also recognising how they are part of wider systems, and how the interactions with these systems are present in the individual’s experience. The analysis highlighted the role of the systems the person is part of, in relation to both their understandings and management of the condition. As the analysis suggested, family narratives can either

inhibit or support the understanding and experience of living with epilepsy. People draw from multigenerational scripts (Rolland, 2005) and an understanding of these can deepen understanding of the individual's experience and management. As stated by Werner-Lin & Gardener (2009, p. 201) "*family illness narratives have a significant impact on family members' responses, myths and worldviews on healing and illness and medicine.*" Rolland's (2005) family systems illness model suggests hearing the meanings of illness within the family and across generations to aid understanding. Such an approach could break the cycle of repeating patterns and of 'stigma coaching' (Schneider & Conrad, 1980) through building understanding and developing alternative perspectives.

For many, the onset of epilepsy will be a new situation for them and their families. Byng-Hall (1995, p. 259) stated "*when the situation is outside a previous experience old scripts are unlikely to be sufficiently applicable to new circumstances.*" Systemic therapy can support the development of new scripts that help the family to cope with the changing experience epilepsy presents.

Consideration of relationships and roles people adopt within these systems may also be important, as highlighted within this research, where a person feels the illness and the changes it has brought present challenges to existing roles, their sense of identity and value. Such an experience for some relationships may be challenging and need support in negotiating these new roles and what they mean for the individuals and the relationship.

Consideration of life stages

The analysis also highlighted the importance of the consideration of life stages. The consideration of life stages and the family cycle will aid understanding of the varying impact of illness at different stages to the individual and the family. As stated by Atwood & Weinstein (2010) illness may be seen as a non-normative event that causes regression where progression is expected. Such changes challenge not only the individual but also the systems they are part of. It may be the anticipation or approaching of life stages that causes challenges or disruption. For example, the decision as to whether to have children which two participants spoke about. This

highlights the importance of viewing illness over the life course and considering within this challenge to transitioning between life stages for the individual and the family or relationships they are part of.

This also highlights that support may be needed at different stages for different people, dependent upon their experience and context. The analysis shows that challenges can be faced across the journey of living with epilepsy, not just at onset. For some, future challenges may cause more disruption and loss than the onset whilst for others the diagnostic process in itself can provide challenges and sources of invalidation, and the diagnosis can serve as a validating experience. Epilepsy presents a changing presence within the individual's life as such psychological support should be considered within this ongoing framework and as suggested by Baker (1997), should be available as part of epilepsy out-patient clinics.

4.2.3 Consideration of the impact upon identity

The analysis suggests the importance of considering the immediate and wider context upon the experience and meaning of onset and living with epilepsy. For some participants onset was spoken about with a sense of 'biographical reinforcement' (Carricaburu & Pierret, 1995) or 'flow' (Faircloth *et al.*, 2004) whilst for others it could be perceived as 'biographical disruption' (Bury, 1982).

Some people will experience onset in adulthood as a 'biographical disruption' (Bury, 1982) which challenges known explanatory systems. The analysis suggests that for some this may be accompanied by a search for, or a naming of, a cause as if to retain a narrative across time. In such cases, a therapeutic approach such as narrative therapy (White & Epston, 1990), in which people are helped to connect experiences and events across time in meaningful ways for that person, may be beneficial. Although there is currently not an evidence base for such interventions, a narrative approach fits within a holistic framework, as recommended by the NSF guidelines for long-term conditions (2005), with a focus on the individual's story and wider context as opposed to the NICE (2004) guidelines main focus upon symptom management. It is suggested that this would help to highlight alternative stories, which as Smith & Sparks (2007, p. 31) state "*the more stories a person has access to, the more opportunities they may*

have to potentially reconstruct their body-selves in more meaningful ways, increase their emotional well-being, and expand their sense of who they are and who they could be.”

4.2.4 The importance of information

The NICE guidelines (2004) state the importance of patients being given adequate information to make informed choices and empower them to manage their condition. However, participants’ experiences, in line with previous research (Couldridge, Kendall, & March, 2001) suggest this is not always happening. Some participants raised concerns about the amount of information given about medication and care suggesting, as found in the Clinical Standards Advisory Group Report on services for patients (1999), that there is still an unmet need with regards to information provision. Participants’ experiences also highlight the importance, as advocated in the NICE (2004) guidelines, of appropriate information being given to women “*to enable them to make informed decisions*” and “*to reduce misunderstandings*” (p.31).

4.2.5 Therapeutic alliance and understanding

In relation to therapeutic and clinical encounters, it may of value to consider that prior to therapy, the individual may have experienced invalidating responses to their narrative that may impact upon the narrative constructed. It may be important to start therapy allowing time for the story to be heard and validated. Allowing this space may also facilitate hearing of the reason for seeking care (Beckman & Frankel, 1984). The response to the research advert suggests there is a keenness to share experiences and have others witness and validate their experiences. However, individuals may initially find it hard to talk, perhaps due to the stigmatising narratives surrounding the illness. Individuals may be very aware of the stigmatising narrative surrounding epilepsy and the societal values that privilege certain types of narrative, which may impact upon the narrative construction and performance. The analysis suggests the vital role of consideration by the clinician of dominant narratives and the active construction and performance within the narrative. Consideration of such factors is crucial within formulation to aid understanding of the individuals’ experience.

4.2.6 Conclusion

The NSF for long-term conditions (DOH, 2005) advocates a holistic approach, however, the emphasis within the NICE guidelines (2004) is still upon symptom management, with referral to psychology only being suggested if symptom management is not 'adequate'. This research suggests that the experience of living with epilepsy diagnosed in adulthood is more than symptom management and psychological therapy may be of value for the individuals and their families, not just when seizure control is "*inadequate*" (NICE, 2004, p.27).

Analysis also suggests that change needs to be implemented at the societal and legislative level if individuals' experiences are to be improved and epilepsy is to be better understood.

4.3 Strengths and Limitations of the study

In this section the strengths and limitations of the current research will be considered, followed by suggestions for future research.

The self-selection of the sample through advertisements with two epilepsy charities needs to be recognised, as this may have led to sample bias due to accessing people who are already connected to a 'community'. The method of recruitment also meant that there was not equal representation of genders or ethnic diversity. Previous research suggests that a more diverse ethnic representation would have been valuable in developing understanding of the meanings and management of epilepsy across cultures (Small, et al., 2005). Having an equal representation of genders may also have enabled further analysis of the role of gendered narratives upon experience and understanding. It would also have been more representative of the general population in which epilepsy is more common in males (Banerjee & Hauser, 2008). In addition, collecting more detailed demographic information such as class, educational and employment history would have added to the contexts available for consideration during analysis, which previous studies have suggested to be of value in consideration of the meaning of illness (D'Houtaud & Field, 1984; Pound, *et al.*, 1998). However,

the sample did include a wide range of ages across adulthood, which was a strength of this study.

As recognised within the methodology section, as qualitative research, the analysis does not seek to have the generalisation befitting research that falls within a positivist framework, rather it focuses upon having maximum variation. The richness of the data allows an in-depth insight into the narratives of living with epilepsy and the heterogeneity of experience. It is also recognised, in keeping with the epistemological position, that any reading is open to several interpretations. As stated by Ricoeur (1976, p. 76) there is “*more than one way to interpret a text*’ and ‘*different but equally valid interpretations are possible*” (Stern, et al., 1999, p. 355). Hence, the reader may have different interpretations to those of the researcher as the author would have different interpretations in a different cultural or historical context (Reissman, 1993); such is the centrality of context upon meanings and interpretations made. However, it is hoped that the diligent application of the methodological rigour enabled trustworthiness and credibility in the researcher’s interpretations.

Due to the dual focus of the analysis and the epistemological position of the research individual participant validation was not sought. There is debate within the literature as to the suitability and usefulness in relation to credibility of member validation (Angen, 2000). The decision not to seek participant validation was made based upon the epistemological position that narratives are co-constructed in a particular context and open to multiple interpretations and also in consideration of the fact, as stated by Reissman (1990, p.1197) “*narratives are always edited versions of reality, not objective and impartial descriptions of it.... and interviewees always make choices about what to divulge*”. In addition, the analysis is the researcher’s interpretation, not a pure reflection or representation of the themes heard; as such it was felt that individual validation would not be suitable. However, all participants were sent the shared plots and storylines of the similarities and differences section to be able to hear the outcome of the research as a collective and were invited to share any comments they had. This was felt to be important in relation to developing understanding and pragmatic use of the data.

A limitation of the study was that only one interview was conducted with each participant. Adopting a longitudinal approach and having several meetings would have enabled more in-depth consideration of the experiences of living with epilepsy and how this is narrated over time. Meeting more than once may also have enabled the development of more of a rapport, which may have facilitated more stories to be shared (Holloway & Jefferson, 2000) For example, in my analysis I commented upon how Katie shared a story of her hallucinatory dreams at the end of her narrative perhaps due to the built rapport. Other such 'hidden' stories may have been shared if we had met more than once. However, the timeframe of this research did not allow for such a methodology.

A strength of narratives is the richness of the data provided. Asking open questions and following the participant's path is less restrictive enabling more of the participants narrative to be heard, whilst recognising these narratives are co-constructed and performed with context and audience in mind (Riessman, 2008; Wells, 2011). However, although the richness of the data is a strength, it this was a considerable challenge to be able to present the individuals' and their experiences within the given word limit. This restricted the number of stories that could be presented. It is hoped that future publications will enable the dissemination of more of the analysis that could not be included within this research.

4.4 Future Research

The analysis suggests that it would be valuable to study narratives of both the individuals and their partners or families. This would give an understanding of the role of family narratives and cross-generational beliefs about epilepsy upon individual narratives, experience and management of the condition. It may also be valuable to seek to have a sample with a diverse range of ethnicities to develop understanding of the range of meanings of epilepsy, as this may relate to management of the condition and access to health care within the NHS. As stated above, it would also be valuable to collect narratives of living with epilepsy over time, to be able to study how the experience may be narrated differently at different points in time. The analysis suggests that the experience and impact may vary with age. Research which focuses

upon the comparison of the impact of diagnosis at different life stages would develop understanding of the experience and possible varying support needs at different life stages.

4.5 Conclusions

This findings of this research make an important contribution to the understanding of the experience of living with epilepsy diagnosed in adulthood. The joint consideration of both what was told and how it was told enable consideration of immediate and wider context in the narratives co-constructed, an aspect which has often been ignored in previous research but which is crucial to building understanding.

The findings suggest the importance of consideration of the individual's life experience and the systems they are part of, in addition to the immediate and wider context in which the narrative is co-constructed in developing understanding of experience and management of living with epilepsy diagnosed in adulthood.

From the analysis several clinical implications are recommended which it is hoped will aid clinicians understanding of the experience and the support needs of people with epilepsy, challenging the current predominant focus upon seizure control. It is also hoped the dissemination of this research will contribute towards broadening general understanding of epilepsy, which the analysis suggests is important, and will also impact upon the individuals' experiences of living with epilepsy.

CHAPTER 5. REFERENCES

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CHAPTER 6: APPENDICES

- A. Literature Search Strategy
- B. University of Hertfordshire Ethical approval certificate
- C. Information Circulated by Epilepsy Action
- D. Approval from Epilepsy Action
- E. National Society for Epilepsy Approval Email and information displayed on their website
- F. Participant Information sheet
- G. Consent form
- H. Background information sheet
- I. Sources of support sheet
- J. Interview guide
- K. Transcription confidentiality agreement
- L. Narrative performance framework questions
- M. An example analysis.
 - i. Examples from each of the stages of the analysis of Melanie's interview
 - ii. Melanie's transcript

Appendix A: Literature Search Strategy

1. Firstly there was an initial exploratory search. This search consisted of a review of relevant books within the university library and searches in Psych Info, Google Scholar and the annual review database. The terms used were:

Epilepsy OR 'chronic illness' AND

Narrative(s); illness narratives; adjustment; diagnosis; 'lived experience';
biographical disruption

2. The second stage involved following up on references within relevant articles and also recording key terms used in these articles. In addition to reviewing other articles published by key authors.
3. At the same time as the stage above I also contacted researchers and clinical practitioners in the field with details of my research question to discuss key references I should be aware of, as well as discussing this with my research supervisors.

From these stages I developed a list of seminal articles and researchers in the field and key words for my search.

4. The third stage involved an in depth review of the literature guided by the criteria and terms detailed below which was conducted over an 18 month period.

The following criteria were used to guide the search.

- a. inclusion criteria

- Studies of adults (18+) with epilepsy
- papers published in English
- peer reviewed journals

- Papers which focus upon the psychological ‘lived experience’ not medical or neuropsychological aspects of epilepsy

Exclusion criteria:

- childhood studies;
- studies of people with epilepsy and an Autistic Spectrum Disorder, learning disability, non-epileptic attack disorder, psychosis, or having any other neurological disorders alongside epilepsy, which were present prior to onset. (In fitting with my participant criteria.)

b. Dates of search: 1995-2011

c. Search terms

The following terms were used with Boolean operators and truncation options to ensure any relevant papers were retrieved.

Epilepsy- seizure; absence; epileptic; tonic-clonic; episode; partial seizure; generalised seizure; epileptic convulsion; fit; epileptic attack; petit mal; status epilepticus

Sub: aura AND epilepsy; déjà-vu AND epilepsy

“Lived experience”- personal experience; events; personal journey;

Narrative- story; story telling; illness narrative; account; narration; narrative act; life story; biography; narrative reconstruction

Adaptation- adapting; coping; changing; adjustment; change; psychological impact; emotional adjustment; social adjustment; psychological adjustment; psychosocial adjustment.

Biographical disruption- disruption

Coping- cope; struggle; manage; get by; function; carry on; resilience (psychological)

Stigma- stigmatising; shame; conceal; concealment; hiding; hide;
physical illness (attitudes towards); disability discrimination; disabled
(attitudes towards)

Culture- cross cultural; customs; beliefs;

Quality of life- sequelae; trajectory; well being; life satisfaction;
lifestyle

Qualitative methodology: descriptive; meaning making; reviews; case
study; IPA; narrative analysis; phenomenology; thematic analysis;
grounded theory; social constructionism; qualitative methods;

d. The following search engines were used:

- Psyc Info
- CINAHL Plus
- Pubmed
- The Pro quest Theses & Theses database
- Cochrane review
- Scopus (contains articles relevant to psychology, social sciences
and life sciences)
- Web of Science (Science Citation Index (SCI and Social Sciences
Citation Index (SSCI)
- Annual Review database
- SIGLE
- Google Scholar

e. In addition to a hand search of narrative and epilepsy journals for the past
year in case of anything not picked up by above searches

f. Citation alerts were also set up associated to key papers through search
engines and also through Google scholar.

g. World Wide Web searches

- Department of Health
- NICE

- Epilepsy Charity websites: Epilepsy Action, National Society for Epilepsy and Joint Epilepsy Council. This lead to access to Epilepsy Professional a bi-monthly magazine.

5. Ongoing review of the following specific journals:

Sociology of health& illness

Social science & medicine

Seizure

Epilepsia

Epilepsy & Behaviour

Qualitative Health Research

Narrative Inquiry

Appendix B: UOH Ethical Approval Certificate

Revised (September 200

SCHOOL OF PSYCHOLOGY ETHICS COMMITTEE APPROVAL

Student Investigator: Lisa Brosh

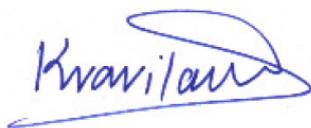
Title of project: Narratives of living with epilepsy in adulthood

Supervisor: Wendy Solomons

Registration Protocol Number: PSY/05/10/LB

The approval for the above research project was granted on 17 May 2010 by the Psychology Ethics Committee under delegated authority from the Ethics Committee of the University of Hertfordshire.

Signed:



Date: 17 May 2010

Professor Lia Kvavilashvili
Chair
Psychology Ethics Committee

STATEMENT OF THE SUPERVISOR:

From my discussions with the above student, as far as I can ascertain, s/he has followed the ethics protocol approved for this project.

Signed (supervisor):

Date:

APPENDIX C: Epilepsy Action information

This is the information which was circulated by Epilepsy Action.

Narratives of living with epilepsy in adulthood

Were you diagnosed with epilepsy as an adult?

Lisa Brosh is a trainee clinical psychologist at the University of Hertfordshire. Her research interest is in the stories of people who are diagnosed with epilepsy as adults. There has been little focus within clinical research upon the individual's experience of living with epilepsy, and how those diagnosed in adulthood understand and adapt to this change to their expected life course.

This research aims to hear personal stories of individuals diagnosed in adulthood. It is an important original piece of research that will help health care professionals to better understand the experience of living with epilepsy, which will be useful in developing services and support for people with epilepsy.

If you would like to know more about this research or how to take part please contact Lisa Brosh by email: lisabrosh@hotmail.com or post: Doctor of Clinical Psychology Training Course, University of Hertfordshire, Health Research Building, College Lane Campus, Hatfield, AL10 9AB.

Appendix D: Approval from Epilepsy Action

Below are copies of the emails confirming Epilepsy Action's support with recruitment for this research.

From: Margaret Rawnsley (mrawnsley@epilepsy.org.uk)

Sent: 29 April 2010 14:44:14

To: Lisa Brosh

Dear Lisa

Thank you very much for your application. I am pleased to inform you that we are happy to help with your project, subject to it receiving ethics approval.

I will draft the copy for the website etc and have this QA'ed and ready for r when your ethics comes through. Although you haven't ticked it, I would suggest that I put something in the October issue of Epilepsy Today. This goes to 12,000 members and will hit the doormats in mid September.

Kind regards

Margaret

To Lisa Brosh

From: **Margaret Rawnsley** (mrawnsley@epilepsy.org.uk)

Sent: 20 May 2010 11:53:47

To: Lisa Brosh

Dear Lisa

Thank you very much for sending through your ethics approval. Details should be on the website in the next few days and at that time I will ask for a link to be posted on the forum. Our Regional Service Manager in the South East has forwarded information to the branches. They only meet once a month, so they may take their time getting back to you. But if you haven't hear anything in the next few weeks let me know. I will also include your study in the next issue of Epilepsy Today. This will be landing from mid-July.

Kind regards

Margaret

Appendix E: National Society for Epilepsy email

Date: Wed, 9 Jun 2010 21:06:19 +0100

From: Emma.Lustig@epilepsysociety.org.uk

To: lisa brosh

Hi Lisa

Apologies for the delay on this. I am pleased to inform you that we can offer to advertise for volunteers for your research recruitment on the website. Would you like to send through some text?

Many thanks

Emma

Web Editor

National Society for Epilepsy

ADVERT INFORMATION:

Were you diagnosed with epilepsy as an adult?

My name is Lisa Brosh and I am a trainee Clinical Psychologist at the University of Hertfordshire. I am interested in the experiences of people who were diagnosed with epilepsy as adults (18+). There has been little focus within research upon how individuals diagnosed in adulthood understand and adapt to this change to their expected life course.

This research aims to hear personal experiences of individuals diagnosed in adulthood. It is an important original piece of research that will help health care professionals to better understand the experience of living with epilepsy and guide improvements in clinical practice.

If you have any questions, would like to know more about this research or find out about volunteering please contact me by email lisabrosh@hotmail.com or post c/o Cathy Lambert, Doctor of Clinical Psychology Training Course, University of Hertfordshire, Health Research Building, College Lane Campus, Hatfield, AL10 9AB.

APPENDIX F: INFORMATION SHEET



Doctorate in Clinical Psychology

INFORMATION SHEET

Research Title: Narratives of living with epilepsy in adulthood.

Introduction

You are invited to take part in research exploring the experience of living with epilepsy in adulthood. To help you decide if you would like to take part, please take the time to read the following information, which explains why the research is being carried out, and what it will involve. My details are at the end of this sheet so you can contact me with any questions you have about taking part.

The researchers

The study is being carried out by Lisa Brosh, Trainee Clinical Psychologist, as part of a Doctoral qualification in Clinical Psychology. The study is supervised by Wendy Solomons, Chartered Clinical Psychologist and lecturer at the University of Hertfordshire.

What is the purpose of the study?

I am interested in how people who are diagnosed with epilepsy in adulthood understand this experience. Epilepsy is the most common neurological disorder in the UK. Most research to date has focused upon seizure control with little focus upon individuals' experience of living with epilepsy, and how those diagnosed in adulthood understand this change to their expected life course.

This research aims to hear personal stories of people diagnosed with epilepsy in adulthood, which may not have been given a voice. It is an important piece of original research that will help health care professionals to better understand the experience of people living with epilepsy. We hope this will also be useful in developing services and support for people with epilepsy.

What is involved?

To take part you will be asked to sign a consent form and complete a brief background information sheet. You will be invited to meet with me to talk. This meeting will take no more than an hour and half. We can meet at a place convenient to you e.g. your own home or at the University of Hertfordshire. If you need to travel to meet with me I can reimburse your travel expenses. During our meeting we will discuss your experience of living with epilepsy, in particular the impact upon how you see yourself and how this may have changed over time. All interviews will be tape recorded and then typed up word for word to make sure I do not miss anything you have said to me.

Who is taking part?

This study will include a maximum of 8 men and women aged 18 years and above who have Epilepsy. All participants must have been diagnosed with epilepsy as adults (18+); had a diagnosis for at least one year; been diagnosed within the last 20 years; and had seizure activity in the past year.

Do I have to take part?

No. Participation is voluntary and you can withdraw from the research at any time.

What do I have to do?

If after reading this information sheet you decide you would like to take part in the research you can contact me via the details below. I will ask you a few questions about the age and year you were diagnosed, and your seizure activity. I am asking these questions as I am looking for up to 8 people who have a similar epilepsy background history. If you then take part, you will be given a consent form to sign. I will then contact you to arrange a suitable time and place to meet.

Will taking part be confidential?

Yes. If you agree to take part in the study your information will be stored in a safe locked location, which will only be accessible by the researchers. The overall findings of the project may be published in a research paper; if your stories are used in the research, I will do my best to conceal your identities for example changing names and recognisable details. However, it is possible someone who knows you well may guess your identity.

If during the interview I have serious concerns about intent to harm yourself or the safety of others I am compelled by my duty of care to inform others. If I have any concerns I will always try to speak to you about these so we can decide together how to let appropriate services (e.g. your GP) know.

What are the benefits of taking part?

From many years of clinical experience and research, we know that talking about events can be helpful. This research will give you an opportunity to speak openly and honestly about your experiences. Research has shown that for some people participating in research interviews can have a helpful effect. Your participation may not have a personal benefit, however, through sharing of your experience healthcare professionals knowledge of living with epilepsy will be broadened benefiting clinical practice.

What are the potential difficulties that taking part may cause?

I am aware from my clinical experience that talking of personal experiences can be emotive and it may cause some discomfort and distress. If this does occur, you will be reminded that you can take a break or stop the interview at anytime. I will use my clinical experience to foster a warm and compassionate environment in which you feel supported to share your experience. We will have time after the interview to discuss your feelings about taking part and answer any questions you have. You will also be given contact details for sources of support should you feel that you require it after taking part.

What if I have questions or concerns?

If you have any further questions about the research, please feel free to contact me via email, telephone or post, details of which are below.

Who has reviewed this study?

This study was reviewed by University of Hertfordshire Psychology Research Ethics Committee and was given ethical approval. (Registration Number: PSY/05/10/LB)

Thank you for taking time to read this.

Contact details of the researcher:

Name: Lisa Brosh Telephone number: 01707 286 322

Email address: lisabrosh@hotmail.com

Postal address: Doctor of Clinical Psychology Training Course,
University of Hertfordshire, Health Research Building,
College Lane Campus, Hatfield, AL10 9AB

APPENDIX H: BACKGROUND INFORMATION SHEET



Doctorate in Clinical Psychology

Background information

Please complete the questions below. If there are any you do not wish to answer or which do not apply to you please leave these blank.

1. Age.....

2. Male or Female (*please circle*)

3. How would you describe your ethnicity?
.....

4. Are you a member of a religious group? If yes, which affiliation?.....

5. At what age were you diagnosed?

6. What was your diagnosis?

7. Are you on medication? y/n

If Yes what.....

8. When did you last experience seizure activity?.....

9. At what age did you have your first seizure?.....

10. What is your marital status:

single in a relationship married separated divorced (*please circle*)

Thank you for your time.

Registration Number: PSY/05/10/LB

APPENDIX I: DEBRIEFING AND SOURCES OF SUPPORT SHEET

(This was given as a double sided sheet with debriefing on one side and sources of support on the other)



Doctorate in Clinical Psychology

DEBRIEFING INFORMATION SHEET

Thank you very much for making this study possible.

This study aimed to explore the experience of living with epilepsy in adulthood. I was interested in:

- How you understood the experience of being diagnosed with epilepsy in adulthood; and any changes to this experience over time;
- Any changes in how you saw yourself and you felt others saw you since the diagnosis; and
- How you spoke about your experience within the interview.

The current academic literature in the field of epilepsy is mainly focused upon seizure control with little research upon the personal stories of those living with epilepsy. It is known that living with epilepsy can have an impact upon all areas of an individual's well being, yet little is known of how people understand this experience. As a health professional this gap is crucial in understanding and being able to support people, who need it, with this process. This research hopes to develop this knowledge with the hope that it will impact upon clinical practice and understanding of the experience of living with epilepsy

SOURCES OF COMFORT AND HELP

- The most immediate sources of comfort and help are likely to be your own family and friends.
- You may also consider contacting your GP who may be able to refer you to more specialised local support services such as counsellors if you feel this may be of benefit.
- You can call the National Society for Epilepsy helpline. This helpline offers a confidential listening service as well as being able to signpost you to local sources of support. The National Society for Epilepsy helpline is: 01494 601 400 and the website is: www.epilepsysociety.org.uk.
- Epilepsy Action has a free phone helpline (0808 800 5050) which offers a confidential service. You can also email the helpline on helpline@epilepsy.org.uk. Information on other supports they offer can be found on their website: www.epilepsy.org.uk
- You can also call the Samaritans which is a national helpline that is open 24 hours. The telephone number is: 08457 909090 and their website is: www.samaritans.org

Registration Number:
PSY/05/10/LB

APPENDIX J: INTERVIEW GUIDE

Opening Question: The conversation we are about to have is part of a study of individuals stories of how living with epilepsy diagnosed in adulthood is experienced over time. I am interested in how you have made sense of your experience, how it may have changed over time, and the impact epilepsy has had upon the way you see yourself and the world. Perhaps, to begin with, you could tell me something about your experience of living with Epilepsy.

<p><u>General Probes</u></p>	<p>You mentioned how....Could you tell me that part of your story in a little more detail?</p> <p>How did you understand this/ that?</p> <p>How was that experience for you?</p> <p>What sense did you make of...?</p> <p>What happened next?</p> <p>How have things changed over time?</p> <p>Can you tell me about.....</p>
<p><u>Topic: Meaning to self and changes over time</u></p>	<p>How would you describe yourself and your life since you were diagnosed with epilepsy? how would you have described yourself before you had epilepsy?</p> <p>Do you think this has changed over time?</p> <p>Do you think it may change in the future?</p> <p>Thinking about when you were first</p>

	<p>diagnosed or started having seizures can you tell me about that time?</p> <p>And now, how has this changed?</p> <p>Do you think there have been any particular experiences that have led to a change in your understanding/ experience of living with epilepsy?</p>
<p><u>Topic: Prior knowledge of epilepsy, beliefs and values</u></p>	<p>Can you tell me what you knew or understood about epilepsy before you were diagnosed? And when you were diagnosed did you think about this?</p> <p>When you were diagnosed what was your understanding?</p> <p>And now has this changed over time?</p> <p>Do you think there are any particular personal values or spiritual beliefs that had an impact upon how you have made sense of and live with epilepsy?</p>
<p><u>Topic: Impact upon the way you see the world/ self/ identity and relationships</u></p>	<p>Can you tell me about how epilepsy has impacted positively or negatively upon your life (socially, professionally, emotionally) and you as a person?</p> <p>Has this changed over time?</p> <p>Thinking back to before you had epilepsy compared to now have you noticed any ways, positive or negative, in which you view yourself differently?</p>

	<p>Can you tell me a little about how you see this changing or remaining the same in the future?</p> <p>I was wondering if you could tell me a little about how your family/partner responded when you said you had epilepsy?</p> <p>What happened next?</p> <p>And now has this changed at all over time?</p> <p>Have you noticed any changes in your relationship with your partner/ closest friends since you were diagnosed?</p> <p>How do you think it may change with time?</p> <p>(If employed) Can you tell me about when you told your employers about your epilepsy?</p> <p>Can you think of any times you've noticed a change in the way colleagues behave towards you since they found out you've got epilepsy?</p>
<p><u>Topic: Stigma/ concealment</u></p>	<p>Who knows you've got epilepsy?</p> <p>Can you tell me about a time you had to tell someone you had epilepsy?</p> <p>Can you recall any times when you had wanted to tell someone about your</p>

	<p>epilepsy then didn't feel able to do so?</p> <p>Are there any people who don't know or you may be hesitant to tell about your epilepsy?</p>
<u>Topic: Reflection/ evaluation</u>	<p>How do you think your life/ you would be different if you had not developed epilepsy at age x?</p>
<u>Topic:Ending</u>	<p>Was there anything related to your experience of living with Epilepsy you wanted to say which you feel you haven't had time to say?</p>

Appendix K: Transcription Agreement



Transcription Agreement

Transcription confidentiality/ non-disclosure agreement

This non-disclosure agreement is in reference to the following parties:

Lisa Brosh ('the discloser')

And

Transcription service ('the recipient')

The recipient agrees to not divulge any information to a third party with regards to the transcription of audio recordings, as recorded by the discloser. The information shared will therefore remain confidential.

The recipient also agrees to destroy the transcripts as soon as they have been provided to the discloser.

The recipient agrees to return and or destroy any copies of the recordings they were able to access provided by the discloser.

Signed:.....

Name:.....

Date:.....



Appendix L: Narrative performance framework questions

The following questions were used to aid analysis of how stories were told.

- Taken from Reissman (2003):
 - Why was the tale told that way?
 - In what kinds of stories did the narrator place himself?
 - How does he/she locate him/herself in relation to the audience, and vice versa?
 - How did s/he strategically make identity claims through his narrative performance?
 - What other identities are performed or suggested?
 - What was the response of the audience, how did she influence the development of the illness narrative, and interpretation of it?
 - How might it be interpreted differently with historicity and social structure in mind?
- Burnhan's(1993) GRRAACCEESS were held in mind to aid reflection upon difference and power. The GRRAACCEESS's are: Gender ,Race ,Religion , Age ,Ability ,Class ,Culture , Ethnicity , Education ,Sexuality, Spirituality.
- Who might be the ghostly audiences? (Minister, 1991)
- In aiding consideration of the language and what this may be communicating the following points were considered guided by Langellier, 1989 and 2001:
 - uses of repetitions, pauses, reported speech, shifts in pronouns, shifts in time (now/present to past) use of vivid detail and uses of gesture.
- How is the account organized? Why does an informant develop her tale *this* way in conversation with *this* listener? Reissman (1993, p.6)
- What is left unsaid or silenced? Why is this story told now? What might be the untold stories? (McAllister, 2001)

APPENDIX Mi: AUDIT TRAIL

Participant: Melanie

Stage 1- Alongside listening to the interview and reading the transcript I read my post interview reflections, excerpts of this are included below.

Personal impact: I felt frustration and anger as she told of her struggles to get a diagnosis and then the relief of getting her diagnosis. I think had I seen her earlier in the year when she was still being pushed from 'pillar to post' it would have been a very different story, perhaps dominated by stories of anger and frustration. I feel I met her at a time when her story is progressive and moving forward as oppose to the struggles of the past few years. Although even as I hear it as progressive I hear the losses and constant struggles to lead a 'normal' life. I felt choked when she said 'I wonder if I'll ever recognise that girl in the mirror' and also by the way she spoke about not only the physical appearance change but the change to her whole life and the strength with which she said 'I hate it' (epilepsy) was very strong and emotive.

Melanie really reminded me of the lady I saw in my CMHT placement. After the interview I found myself thinking about her. I feel this will be important to bear in mind through the analysis so as not to confuse or blur their stories or impose her experience onto Melanie's account.

What were the most strongly heard stories? Loss of who she was; who she was before (lively, active, social) compared to now- what epilepsy has 'taken' from her; anger at the NHS- many experiences of being let down/ not believed; the positive experience of the epilepsy hospital being with others experiencing seizures and doctors who 'believed' her.

Stage 2: Memo's The details below are excerpts from my notes following reading through the transcript several times focusing upon both the content and the 'performance'.

Initial thoughts: The start of her narrative focuses upon her journey and the struggles to getting her diagnosis and being validated that she couldn't 'turn it on and off'. The importance of the diagnosis, even though it hasn't lead to any positive changes in the impact epilepsy has upon her daily life, felt palpable.

How was the story told?

- Often use of laughter during emotional stories or when Melanie perhaps felt uncomfortable.
 - For example, near the beginning her account she says '*So, it...four years of not knowing and people telling me that it was, kind of, it was in my head, it wasn't what I thought it was and being in and out of hospital and being pushed from one doctor to another, erm, so yeah, it's not fun, at all. [Laughs].*' (12-15)² The tone of this did not match with the experience which sounded to be quite frustrating but was told in an upbeat tone.
- She talks of using humour to make others feel more comfortable and her to be able to talk about it. This perhaps links to the humour and tone in the account. I wonder if there is an untold story, hidden beneath the use of humour which she feels is less 'acceptable' or able to tell in this context?
- I wondered if the laughing and remaining upbeat may also have been to make me feel comfortable, perhaps fearing I may also find her experiences of epilepsy scary or show the look of 'pity' she spoke of seeing in people's eyes.
- At one point she talks of a changing relationship with the epilepsy and how she tries to think positively. I wondered if this was drawing from narratives of 'acceptable stories?' That this is the type of story she 'should' be telling and given it comes later on in her account which perhaps experience has taught her is more acceptable.
 - *hopefully, I say hopefully, I try to be positive. Yes, it will change!*
[Laughs] (510)

² Numbers in brackets are the line numbers on the manuscript.

- *'it's not so much of a demon anymore, it's just there, it's learning to live with it alongside rather than letting it control and run my life now' (636-637)*

In what kinds of stories did she place herself? I feel that Melanie placed herself in stories of struggles in which she was struggling to be heard, at times it sounded as if it was hard to keep this battle going. She said at times she almost walked away but at other times her tone also suggested a determination that she knew there was something wrong- despite the many invalidating experiences- and eventually she would find out what it was. She knew she couldn't 'turn it on and off. '

How was it organised: Melanie starts with her lack of faith in the NHS and her struggle. From the start clearly stating her position and passion against the epilepsy- *'it's like having your legs chopped off'* (37-38) and her *'hate'* Following a question about her onset she takes me through a detailed narrative from the shock and disbelief of the first seizure through her journey to diagnosis. This part dominates the interview. The later part is my questions, following up on her mum having epilepsy, people's reactions and changes since onset in her life and the way she sees herself.

Repetition of stories/ themes: I felt a repetition of message- her anger/frustration at the NHS; the long journey; and the change in her.

What was my influence upon the telling? I wondered if she felt she needed to tell an upbeat story – protect me/ make me feel comfortable like she spoke of with her brother? She spoke of how people with epilepsy understood her, being in that hospital was somewhere she felt understood/ comfortable. I wonder how this shaped the story constructed- telling to someone without epilepsy who works clinically for the NHS.

What felt important to be heard/ was most strongly heard?

- The journey, the struggle, not being understood or supported;
- The mistreatment by the NHS and the anger at the doctors.
- Her loss of her 'normal' life; almost grieving –still feeling lost- not recognising herself in the mirror. she brings this storyline in very early in her narrative. The impact upon who she is and who she was. As if the epilepsy has

taken away part of who she was- not just through the physical limitations but also how she feels about herself.

- The turning points of doctors who believed her; staying in the hospital with other people with epilepsy; the supportive employer and children she now works with
 - *I found a really good doctor at my practice who was actually willing to sit there and listen and help and he was brilliant and that, kind of, restored my faith a little bit in what's been going on because he was very much...very proactive and really wanted to help and actually seemed like he really cared about it. (186-190)*
- The family narrative-epilepsy is present yet not spoken about or spoken about with humour.

Stage 3-Global impression

Melanie's narrative spoke of a four-year rollercoaster journey to get a diagnosis. Along this journey, there were mainly narratives of not being believed and being let down. Finding doctors who believed her, getting a diagnosis and a supportive employer were significant turning points in her journey. Melanie spoke throughout of what she had lost physically, emotionally and in her lifestyle. She spoke of the daily struggle she faced and how much she hated the epilepsy. Yet there was also indication of a fighter who wanted to be able to recognise herself in the mirror again. Melanie spoke of using humour to help herself cope and also as a way to help others feel more able to talk about it and prevent the look of pity or fear she has experienced seeing in others. This theme of using humour to help others feel more comfortable was also present in her telling of the story in which she often laughed or used reported speech to engage her audience and perhaps make the story more comfortable to hear.

Stage 4 Focus upon the storylines

Storyline 1- The rollercoaster ride to getting a diagnosis.

A few of the points in her story which linked to this storyline were:

- She starts with the length of this journey, setting up the context for her narrative
- The telling felt like a rollercoaster. Melanie draws the listener in through her use of reported speech and intonation- sharing the highs and lows of her rollercoaster. The telling of the doctor who listened was like a peak in the ride and then he left and the ride falls with stories of not being given time, people not understanding and not listening. These were the low parts of the rollercoaster ride. Then change again when the consultant says they will keep having her back until they understand. Her relief that finally she has found someone who listens and cares.
- Her struggle to tell her story which she speaks of professionals perhaps not appreciating. NHS system where a certain type of story is privileged (more ‘acceptable’) and expected to be heard. The difficulties for people unable or whose stories do not fit this format.
- The role of context and the point in her ‘rollercoaster’ upon the telling. She was at a point where she had her diagnosis- perhaps leading to a more positive tone and a resolution to her story. In contrast to had I met at earlier points where her story was being invalidated.

A few of the quotes that I highlighted on the transcript for this storyline:

four years of not knowing and people telling me that it was, kind of, it was in my head, it wasn't what I thought it was and being in and out of hospital and being pushed from one doctor to another, erm, so yeah, it's not fun, at all. [Laughs] (12-15)

I have no faith, well I had no faith, in the NHS because they were very much...because they didn't know what it was, then, it wasn't anything, it was, kind of, like, you know, pushed under the rug, (17-19)

so a few months passed, I kept trying to chase it up and then they lost my medical notes. You know, that really...small amount of miles, they managed to lose it so, not only had they lost my notes the first time it had taken me six months to get my MRI scan. (124-127)

I was, kind of, stuck in limbo (116)

it's really hard trying to, you know, hash it all up and, kind of, put it in order because I struggle with remembering things and trying to remember exactly what happened and who I've seen and when I've seen them because they ask the same things, like, when was your first seizure, how was it, how did you feel and I don't know, I was asleep! (133-137)

It was another, kind of, rollercoaster ride (141)

I ended up reading what one of the junior doctors {croaky/teary voice} had written and basically he'd put that, erm, they'd seen nothing and they basically said that I could turn it on and off when I want. (162-164)

Storyline 2: The losses and changes

Some of the experiences and telling that link to this storyline are:

- Her narrative seems to have a thread of loss almost from the very start when she talks of what epilepsy has taken away and the change in her.
- Loss of her life- I try to lead a normal life- implicitly telling that for her life now isn't 'normal' and contrasting herself pre and post epilepsy. Her current story is perhaps in contrast to dominant narratives which she draws from.
- Speaking of not wanting to talk about how her life may be different indicates it is a loss still felt and almost still being grieved for.
- Loss of independence and spontaneity at a time when such values are 'expected' and privileged.
- Loss of recognising herself and some parts of herself- in a physical sense as due to medication she has put on weight but also in her lifestyle from being someone out going to someone almost scared to use the phone.
- Loss of the ways others see her and the 'looks of pity'.
- Loss of connection to body in referring to doctors asking about seizures and her comment of how would she know?

Some of the quotes that I highlighted on the transcript for this storyline:

its like having your legs chopped off because you want to do stuff but you can't. (38-39)

I don't have as much confidence, I'm not outgoing any more, I'm very, erm, what can I say, erm, it's not shy, it's more reserved about doing things (32-33)

you can't get there easily, you have to rely on somebody else to take you there, which makes you feel bad and you don't have enough money to go out and do things and you don't want to go to new places because then you have to explain, you know, why you are like you are and it just sucks, its horrible! I wouldn't wish it on my worse enemy. (39-43)

I try to live a normal life (45)

I look in the mirror and think that's not me, not only physically, like, I hate the way I look in a mirror but looking in there I think, you know, that sparks gone, you know, very mischievous and I'll go and just look and think, I don't know that person in the mirror. (419-423)

I shy away from doing things, before I wouldn't have thought twice about getting on the phone and, you know, speaking to somebody, now I don't like using the phone. (452-454)

everything is like a military operation, nothing is spontaneous and that just takes the fun out of everything for me. (468-469)

Stage 5: Individual narratives

Extracts from each of the storylines written are included below.

Storyline: The rollercoaster ride of getting a diagnosis

four years of not knowing and people telling me that it was, kind of, it was in my head, it wasn't what I thought it was and being in and out of hospital and being

pushed from one doctor to another, erm, so yeah, it's not fun, at all.

[Laughs] (12-15)

Melanie starts and ends the narrative of her journey to getting a diagnosis with the time it's taken, '*four years*'. Her narrative is full of stories of not being believed, in one instance of being told she could '*turn it on and off*', not being listened to and not being understood. Melanie places herself within stories of struggles and frustration, as if she is battling the system yet at times finding it hard to be able to do this and at times losing faith in this fight. The narrative of her early treatment seemed saturated with stories of frustration and mistreatment. The '*rollercoaster ride*' took longer than she was told or expected it to and throughout this time her seizures continued and worsened with her talking of feeling like she was '*in limbo*' and constantly retelling her story. I felt like I was on that rollercoaster with her. I recall feeling relief when she spoke of the first doctor that believed her and was going to help and then he left and the ride plummeted again. At one point in her narrative Melanie says '*maybe I'm dramatising it all*', perhaps communicating a fear that in this context of sharing her story with an NHS employee she may also not be believed.

Melanie described the frustration at having to always repeat her story, saying, '*it's really hard trying to, you know, hash it all up and, kind of, put it in order because I struggle with remembering things*' with health professionals having no appreciation of the cognitive and emotional impact of relaying this story. There was an anger and frustration across these stories and then a change in tone to relief and gratitude when she went to the specialist hospital where the doctor reassured her they would keep asking her in until they understood what was happening. Yet even with this reassurance, she says, following having a seizure at the hospital, '*she showed me the print out and where it had spiked and on what side and it was just such a relief.*' This relief of having a seizure and then getting her diagnosis just days later is palpable endpoint in this story.

Storyline-the losses and changes

I look in the mirror and think that's not me, not only physically, like, I hate the way I look in a mirror but looking in there I think, you know, that sparks gone, you know, very mischievous and I'll go and just look and think, I don't know that person in the mirror. (419-423)

Melanie speaks strongly of a loss of who she was following the epilepsy, referring to it '*like having your legs chopped off*' part of her has been taken away to the extent that she no longer recognises herself in the mirror. She stories the loss in many areas of her life from the loss of confidence to loss of independence, to the loss of spontaneity and *military precision* now present in her life which she refers to as taking the fun out of everything. She speaks of trying '*to lead a normal life*' contrasting her current life to that before epilepsy and seeing the latter as 'normal'.

Melanie speaks of using humour to help her cope but also to help others cope indicating that perhaps she thinks of epilepsy as something people find scary. She talks of the guilt for the extra support she now needs and the burden this places on others. There is also an indication of self blame in a comment of how she links her active social life and work to the onset of the epilepsy stating '*I don't think anybody was shocked*' suggesting she partly blames herself. Melanie mentions that her mother had epilepsy but that it was never spoken about and her fear that her mum may feel she'd given it to her. Such stories suggest that the use of humour with her brother and others may also be due to a learnt narrative that epilepsy is something not to be spoken about and also following experience of others reactions of shock or pity. Melanie speaks of finding benefit in her stay within the specialist hospital and working with children with epilepsy in being surrounded by people who had similar experiences who understand her more suggesting her narrative in this context of someone who doesn't have epilepsy maybe constructed for someone who would not understand.

Stage 6- Connection to the collective plots and storylines.

Following completion of the analysis of all eight participants accounts the narratives were considered collectively. Reading across the narratives three broad shared plots were identified beneath which storylines highlighted differences and similarities across participants in content or performance. Below I have included some of the quotes and stories that fit within each of the shared plots for Melanie.

Stories of onset

The ‘disruption’

- Melanie starts her account with the onset. Her stories have a theme of ‘disruption’- epilepsy took her life as she knew it away.
 - *‘so from having a very active and a bit mad life sometimes from, you know, late teens up to being mid twenties, having that just taken away from you is just awful.’ (34-36)*
 - *‘It’s like having your legs chopped off’ (38-39)*
 - *‘it’s, erm, kind of, hard to talk about it, [laughs] erm, it...it changed me a lot’ (21-22)*
 - *‘I don’t have as much confidence, I’m not outgoing anymore’ (31-32)*
- When reading across the transcripts this position was in contrast to Katie’s telling of onset as an ‘affirmation’ of stories of self and how it made sense of earlier experiences. Fitting more with Claire’s stories of onset and disruption.
- Melanie starts her narrative with the onset, her shock and the impact of the *‘four year rollercoaster’* (141)
- She speaks of the shock of the first seizure and hearing through her friends. Her use of reported speech and long detailed story of her first seizure draws the listener in to her story.
 - *I said to them, ah, I’ve just had such a weird dream and he was, like, sat on the end of my bed and he hadn’t slept all night and I was, like, what are you doing? And he went, you had a seizure in your sleep and I went, no I didn’t! (61-64)*

- She talks of disruption to her working life- the change of being signed off work and being at home from working a very full week. This positioning was contrasted to the way Sarah spoke of ‘fighting’ the disruption and dragging herself into work.
- Going back to stay with parents in the initial time following first seizures. (contextualised by her pre-epilepsy independent life working with bands to living at home with parents)
- Story of onset is the start of the rollercoaster of tests, different messages being given and not really understanding or being understood.
- It was told initially in quite a performed way in relation to the actual onset but then with a tone of frustration and anger at the lack of a clear message as to what it was and how it could be treated.
- The story sounds as if she is constantly battling and trying and yet not continually being misunderstood and ignored. For example, the MRI scan which was meant to be done immediately but took 6 months. These doctors take on an almost demonised figures in contrast to the later GP and the specialist hospital doctors.

Living with epilepsy

- Sense of what it had taken away. She could no longer work in bars, go off touring etc and the change to her lifestyle from a well paid job to having to watch her spending and perhaps ‘depend’ on her boyfriend and family more.
- The loss- not recognising self in the mirror. This seems to link to the physical loss-she speaks of having put on weight due to the medication and her change in lifestyle. However, I interpreted this as also relating to not recognising herself in terms of her daily life and struggles. For example, the change from touring with bands and being out going to worrying about going to the gym or using the phone.
- The dependency, feeling of being a burden-‘*demoralising*’ ..(199) how friends say, ‘*I’ll give you a lift home and I’ll wait with you*’ and feeling that ‘*they*

shouldn't have to do that,' (432-434) 'you know, I should be able to do that by myself.' (436)

- loss of independence and '*military precision*' and the contrast to her life pre epilepsy to now
 - *everything is like a military operation, nothing is spontaneous and that just takes the fun out of everything for me, you know.* (468-470)
- The daily struggles e.g. shopping, making a phone call. The things she used to do without thinking are now challenges.
 - *I used to be able to go out and go shopping and buy myself stuff, I can't do that now, I have to be very careful what I spend money on, plus I can't get out to go shopping half the time, it's very much...I need to do it on the internet but then if I have a dysphasia attack I just sit there and I get really frustrated because I can't read and I can't understand why I can't read.* (482-487)
- The desire to feel differently about it that she will move on
 - *it's not so much of a demon anymore, it's just there, it's learning to live with it alongside rather than letting it control and run my life now* (636-637)

Meanings

- Family narratives
 - Melanie mentions that her mother had epilepsy but that it was never spoken about and now she doesn't talk that much to her mother about her own epilepsy. She mentions fear that her mum may feel she'd given it to her '*the last thing I wanted to do was tell my mum because she's the kind that will just fret over it and feel that she's given it to me and it's hereditary and all sorts! [Laughs]*' (92-94) This is a storyline that is also heard within Emma's account and Claire's story of her parents calling epilepsy 'her illness.'
 - She mentions others in her family (cousins) have epilepsy yet they are not present in her story of getting a diagnosis or of her understanding of epilepsy suggesting perhaps it wasn't spoken about? As with her

mum perhaps it was something known about within the family but not to be spoken about.

- Epilepsy as something others might be scared of
 - *I do feel that there is a stigma about it, you know, you say you're epileptic and people's faces change and you just see it, it's, like, if you say you've got cancer, people are like, oh right, okay, if you say you've got epilepsy, people are, like, ah, kind of, look at you funny, it's people don't know much about it and I think they get scared if they see somebody have any type of seizure. (655-660)*
 - This storyline is also heard in the way she talks about her stay in the specialist hospital and how seeing seizures became 'normal' and part of the day. There seemed to be a sense this was a relief and something that made her feel comfortable in the hospital to be with others sharing part of her experience.
 - Her position that others (who do not have epilepsy) may be scared of it is in contrast to the something 'normal' storyline and also the something others used to be locked up for. The historical narratives not being mentioned within Melanie's narrative. Her storyline of something others would be scared of is linked to her experiences of people's reactions. Speaking in this context of others being scared.
- The social meanings of epilepsy is perhaps associated to her use of humour in talking about her epilepsy
 - *I do take the mick out of it and I find it easier to laugh at than to get serious about (393-394)*
 - *sometimes the pity look and people talk to you different, you know, if have to get on a train and because I've got a disabled rail pass, people talk to you like you're completely out of, you know, off your head and it's very much the, can I get you anything and I'm, like, I'm epileptic, I'm not deaf or, you know, a child, don't speak to me like one. (386-391)*

Appendix Mii : Transcript: Melanie

For purposes of anonymity the transcript is only included in the examiner's copy.

The transcript was pages 220-234. These pages have been removed in this copy.