Major Research Project

Narrative Accounts of Family Caregivers of Adults Diagnosed with

Non-Epileptic Attack Disorder

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CONTENTS

1   Prologue: A beginning

"...stories matter. So...do stories about stories"

(Geertz, 1986, as cited in Freedman & Combs, 1996, p.19)

Starting a new research project is akin to starting a new story (Connelly & Clandinin, 1999) and the thesis to follow is my story of the work that I have engaged in over many months. In retelling this story and the stories from the carers whom I interviewed, I am aiming to engage with the reading community in a way that offers "possibilities...for new directions" (Clandinin & Connelly, 2000, p.189) and ultimately for "growth and change" (Clandinin & Connelly, 2000, p.71).

Before I invite you to share in my story, I would like to take the opportunity to honour some of the individuals who have travelled with me throughout my research journey...

To Nick Wood, for your continued support and encouragement over the past year

To Dr Sallie Baxendale, Dr Markus Reuber and Corrine Squire for sharing your professional expertise on the subject

To the carers whom I interviewed for your generous sharing of stories and to NEAD Trust for allowing me to recruit through your charity

To my friends and colleagues for your continued encouragement and patience

To Dave, for your love, support and your amazing ability to help me put things into perspective

To my Mum and Dad for your invaluable support throughout this project and to all my family for always being there for me

2 Abstract

The experiences of family caregivers of adults diagnosed with Non-Epileptic Attack Disorder (NEAD) are under-researched. To address this lack of research and the Department of Health's (DOH) aim to focus on the experiences of caregivers to inform the development of appropriate services (DOH, 2010), this narrative inquiry focuses on the stories told by eight caregivers of adults diagnosed with NEAD.

Each narrative, which was collected through loosely structured interviews, was analysed from both a content and performative perspective. Multiple readings of the narratives revealed that caregivers told two different story 'types' about their experiences: stories of 'biographical continuity' and stories of 'biographical disruption'.

These findings are discussed in relation to the relevant literature and clinical implications. Methodological limitations and directions for future research are also presented. The study provides a valuable insight for any professional working with caregivers of individuals with NEAD and it is hoped that this research will promote dialogue amongst professionals and readers.

3   Introduction

"We see individuals as living storied lives on storied landscapes" (Clandinin & Connelly, 2000, p. 24)

I will open this thesis with some background information about my theoretical position, use of language and the personal and social significance of this research as, in line with Clandinin and Connelly (2000), I recognise that my research interests came out of my own "narratives of experience" and have shaped my "narrative inquiry plotlines" (p.121). The subsequent chapters will focus on the literature review, methodology and the findings of the study.

3.1   <u>My theoretical position</u>

A postmodern and social constructionist epistemology, in which I include a systems perspective, have all influenced the thesis. The latter perspective, in particular, with its emphasis on the idea that all experiences are both individual and relational and that a change in one part of a system can lead to changes in other parts (Hoffman, 1985), influenced my motivation to consider NEAD from a relational perspective. Postmodernist ideas, such as those which challenge the modernist idea of a knowable external reality also encouraged me to focus on 'local' narratives, rather than aiming to look for 'grand truths' (Barker, Pistrang & Elliott, 2008), and to focus on the multiplicity within individuals' stories: multiple views, multiple possibilities and multiple lives (Dickerson, 2010).

Finally, social constructionist ideas, which begin with a "radical doubt in the taken-for-granted world" (Gergen, 1985, p.267) and argue that all knowledge is historically and culturally specific and socially negotiated through language (Gergen, 1985), encouraged me to attend to stories in context (cultural, as well as individual stories). This perspective also understands that 'selves' are socially constructed through language, emerge from discourse (Kogan & Gale, 1997) and are maintained in narrative (Freedman & Combs, 1996). It also posits a 'decentered' or a dialogical 'self' (Bakhtin, 1986, as cited in Kogan & Gale, 1997). Thus, in contrast to the idea

that people have only one 'identity' connected to an autonomous 'self', this perspective argues that the 'self' can exist only in relationship to some other (Josselson, 2011) and that people have access to multiple identities that are context dependent (Dickerson, 2010). These assumptions have guided my understanding of 'identity' throughout this thesis.

3.2 <u>My use of language</u>

Throughout this thesis, language is understood as being a "vehicle for meaning" and the "site where meanings are created and changed" (Taylor, 2003, p. 6). Language is also understood as being influenced by our social and personal histories and contexts and thus, the contexts in which words are used may alter their meanings (Henderson, 2001). In line with this, it was therefore important that I made a number of decisions regarding my use of language in this thesis.

Firstly, I have chosen to combine both an academic style of writing (third person), with a personal voice (first person). In particular, this is due to the fact that scholars have advocated that the use of the personal voice enables the author to form a closer relationship with the reader and effectively and appropriately remind the reader of the researcher's presence and influence in the stories told (Gergen, 2000; Tracy, 2010; Webb, 1992).

Secondly, drawing on my perspective that language and words have multiple meanings that are dependent on contexts, I have chosen to present some words e.g. 'identity', 'self' and 'quality' enclosed within single inverted commas to highlight their multiple meanings. I have also avoided using the word 'patient' (unless it is used within the context of an author's quote) that dominates the medical and psychological literature on NEAD, as I believe this undermines the multiple and layered aspects of individual lives.

Furthermore, to ensure consistency, I have chosen to use the term 'carer' or 'family caregiver' to refer to the participants in this study i.e. individuals "who provide informal regular help and support to another person" (Henwood, 1994, p.3). However,

in using this term, I am mindful of its multiple meanings and align myself to Bytheway and Johnson's perspective (1998, as cited in Henderson, 2001) of 'carer' as a social construction: "a category created by...policy maker and researchers" (p.241). Thus, I recognise that some individuals may not define themselves using this label.

Finally, I am mindful that many labels and synonyms have been used to refer to non-epileptic seizures and that many of these, such as 'pseudoseizures' have been deemed highly offensive by individuals with the condition (Stone et al., 2003) and have led to the condition being dominated by discourses and pejorative connotations relating to the idea that seizures are 'put on', fake or deliberately manufactured. As I wished to avoid words that may contribute to problem saturated dominant narratives about the condition, I referred to the research literature to help me decide what may be the most acceptable definition to use. My decision to adopt the label 'Non-Epileptic Attack Disorder' was influenced by a study by Muller, Merschhemke, Dehnicke, Sanders and Meecke (2002) who carried out a survey with individuals diagnosed with NEAD and found that they indicated that 'Non-Epileptic Attack Disorder' was the most acceptable term. Furthermore, LaFrance, Rusch and Machan (2008) identified in a survey to treatment providers that this term was also most frequently used by healthcare professionals. Whilst I am mindful that professionals have recently argued that 'psychogenic nonepileptic seizures' is now the preferred term (Benbadis, 2010), I have chosen to continue using the label 'NEAD' as this is the term used by the charity from which I recruited.

3.3   "A worthy topic"

Included in her eight criteria of 'quality' in qualitative research, Tracy (2010) argued that good qualitative research is "relevant, timely, significant, interesting or evocative" (p.840). She also wrote that "worthy topics...grow from timely societal or personal events" (p.840). Whilst I will be returning to issues relating to the 'quality' of my research in the methodology section, I hope to briefly orientate the reader to both the personal and social significance of this research.

3.3.1 Personal significance of the research

For me, the subject of this thesis stems primarily from my own personal story of sharing experiences with my older sister with severe learning disabilities and epilepsy. Firstly, from a very young age, I experienced how her condition led to many changes in our family and in our relationships with one another and I recognise that this has strongly influenced the stories that I carry though life and my tendency to always consider the relational and multi-factorial aspects of experiences.

Secondly, I am mindful that through this experience, I entered the profession of Clinical Psychology with a relatively comprehensive understanding of epilepsy and I recall the confusion that I experienced when I began working at an assessment unit for adults diagnosed with epilepsy and NEAD and learnt that individuals could have seizures that were not associated with epileptiform activity in the brain. I was struck by my recognition that my confusion was shared by many family members of adults with newly diagnosed NEAD. I also noticed that there was often a tendency within the service to adopt an individual perspective, at the expense of a whole family perspective and sensed that the experiences of many family members and friends were overlooked.

In approaching this research, I am mindful that these experiences inevitably influenced the stories that I brought with me to the topic and my interactions with my participants, including the ideas that the onset of a seizure disorder may have significant and life changing consequences on family caregivers and that in a Western culture dominated by biological understandings of illness, NEAD may be a confusing diagnosis for caregivers to understand. I endeavoured to reflect on these possible influences throughout the research process.

3.3.2 Social significance of the research

Over recent years, 'care' has received a lot of attention in legislation, policy and practice. This is reflected in the range of policy documents that have been produced, including *Carers and their rights* (Clements, 2009), *Caring about Carers* (DOH, 1999), *Carers at the heart of 21st century families and communities* (DOH, 2008), and

'Recognised, valued and supported: Next steps for the Carers Strategy' (DOH, 2010). This most recent document focused on the needs of being a carer who are described as 'embodying' "the spirit of the Big Society" (p.2), whilst also recognising that such a role can "provoke a complex mix of emotions. It can be both rewarding and frustrating....[and] costly in life changes, financial security and health" (p.2). It also stated that the "government recognises and values the contribution of carers" (p.2) and that "supporting carers' well-being is therefore in all our interests (p.2)".

However, despite the increasing focus on the needs of the 'carer', there is a relative silence in the research literature about the stories and experiences of carers supporting adults diagnosed with NEAD, thus implying that there is limited research to inform services and health professionals in their work. It is possible that the silence of caregivers within this field may be a consequence of the traditional bias in research towards the individual with the condition, in addition to the fact that it is a condition that is relatively neglected (UK Parliament, 2010) and poorly understood within society and lacks well researched guidance (National Institute for Health and Clinical Excellence (NICE), 2009).

Sartain, Clarke, & Heyman (2000) have argued that contemporary society often "makes a value judgement about the relative worth of 'knowledge'" and that "in the practice setting, professional knowledge becomes privileged and the parental discourse is only secondary to professional knowledge" (p.920). However, policy documents have indicated that the "circumstances of every carer are unique and that is why there is an overriding need to personalise support to fit around individual and family preferences" (DOH, 2010, p.3) In keeping with this, this thesis aims to break the silences of family caregivers of adults diagnosed with NEAD and listen to their stories. Given that a number of researchers have advocated for the use of family therapy in the management of NEAD (Archambault & Ryan, 2010), there is clearly a need to bring the stories of family caregivers of adults diagnosed with NEAD into the research field. It is hoped that this will better inform service providers and facilitate a closer connection and greater understanding by professionals working with this client group.

4 Literature Review

The literature review strategy and the list of databases searched are provided in Appendix A.

The literature review aims to share some of the understandings that already exist in the landscape surrounding NEAD and the experiences of family caregivers of adults diagnosed with NEAD. Drawing on the narrative metaphor that "in any life there are always more events that don't get storied than there are ones that do" (Freedman & Combs, 1996, p.32), I recognise that I can only share some understandings and provide one particular narrative construction of the topic, of which readers will inevitably draw their own meanings from.

I will begin by introducing the reader to the topic of NEAD and will then follow this with a discussion of the literature surrounding family experiences in the wider context of chronic illness. Finally, I will explore the limited research on the family within the context of NEAD and identify the current gaps within the research literature, my rationale for the research and my research questions.

4.1   Introducing NEAD

4.1.1   Definitions & Epidemiology

NEAD is defined as a condition by which individuals experience "episodes of altered movement, sensation or experience resembling epileptic seizures but not associated with ictal electrical discharges in the brain" (Reuber, 2009, p.909). They may be physiological or psychological[1] in nature (Gates, 2002) and it is the latter subcategory that this thesis focuses on.

Nonepileptic seizures are very common, representing approximately a third of referrals to epilepsy centres (Benbadis, 2010). Whilst no studies have been completed in the United Kingdom (UK), the estimated prevalence of NEAD amongst the general population of the United States (US) is thought to be 2 to 33 per 100,000 (Benbadis & Hauser, 2000) and the incidence is thought to be 1.4 per 100,000 in Iceland (Sigurdardottir & Olafsson, 1998) and 3.03-4.6 per 100,000 in the US (Szaflarski, Ficker, Cahill & Privitera, 2000). Studies have indicated that NEAD is diagnosed most commonly in females, with studies reporting a 4:1 female:male ratio (Gates, 2002) and in individuals between the ages of 15 and 35 (Krumholz & Niedermeyer, 1983).

4.1.2   Diagnosis & Aetiology

NEAD is typically diagnosed following the exclusion of epilepsy, using video electroencephalogram (VEEG) monitoring during seizures (Reuber & Elger, 2003). The diagnostic process is often challenging and lengthy, with some studies indicating an average of 7.2 years between onset of seizures and diagnosis (Reuber, Fernandez, Bauer, Helmstaedter & Elger, 2002). Furthermore, individuals often have a diagnosis of epilepsy for several years before they learn that this diagnosis is inaccurate and subsequently receive a diagnosis of NEAD (De Timary et al., 2002).

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[1] Approximately 90% of non-epileptic attacks are psychological in nature (Gaynor, Cock & Agrawal, 2009).

Contemporary theories regarding NEAD presume a psychosocial origin (LaFrance & Devinsky, 2002) with most experts understanding NEAD as being an unintentional manifestation of emotional distress (Reuber, 2009). There is a lack of consensus as to whether NEAD is a problem characterised by dissociation or a form of somatization (Reuber & Elger, 2003) and this debate is reflected in the fact that the International Classification of Diseases (ICD-10; World Health Organisation, 1992) characterises NEAD under the heading of dissociative disorders, whereas the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV-TR; American Psychiatric Association, 1980) places them under somatoform or conversion disorders. Whilst a number of etiological models for NEAD exist including psychodynamic, family systems, learning theory, stress, psychosomatic and 'organic' models (LaFrance & Bjornaes, 2010), Reuber (2009) proposed that NEAD is best understood based on a biopsychosocial, multi-factorial model, which aims to consider the predisposing, precipitating and perpetuating factors that commonly interact in relation to NEAD.

In terms of possible predisposing factors, several factors have been linked to NEAD, including childhood sexual and physical abuse (Fiszman, Alves-Leon, Nunes, D'Andrea, & Figueira, 2004), the presence of a fearful attachment style (Holman, Kirby & Duncan, 2008), a 'borderline personality disorder' (Lacey, Cook & Salzberg, 2007) and dysfunctional family interactions (Moore, Baker, McDade, Chadwick, & Brown, 1994). Bakvis, et al. (2009) have also provided some evidence for a possible biological vulnerability to NEAD. In relation to possible precipitating factors, research has found a link between an accumulation of recent stressful negative life events in people who receive a diagnosis of NEAD (Binzer, Stone, & Sharpe, 2004), including factors such as separation from family members, job losses and relationship difficulties (Reuber, Howlett, Khan et al., 2007). This may point to why NEAD is more commonly diagnosed in individuals between the ages of 15 and 35, when such factors may be more likely to occur. Finally, in terms of perpetuating factors that inhibit the ability to gain control over seizures, Reuber (2009) highlighted that research points to the role of anxiety and avoidance, in addition to isolation and emotional distress in maintaining the seizures.

There is very scant data on the cultural aspects of NEAD. However, in summarising the cross-cultural research from Turkey, India and Puerto Rico on conversion and somatoform disorders (that include a high proportion of NEAD-like phenomena), Martinez-Taboas, Lewis-Fernandez, Sar, and Agarwal (2010) highlighted that similar findings have been reported cross-culturally, with NEAD-like phenomena appearing deeply embedded in family structures and dynamics and being associated with childhood trauma, disturbed attachments and dependent relationships. They argued that more cross-cultural research is needed in order to improve understandings about NEAD.

Whilst there continues to be a debate about whether NEAD should be positioned within the field of psychiatry or neurology; which is likely to be fuelled by the dominant 20th century biomedical model and the centrality of mind-body dualism in Western society; I believe that the biopsychosocial model provides a potentially comprehensive understanding of NEAD. In particular, I think that it is a helpful model in encouraging individuals and professionals to move beyond the problematic issues of mind-body duality and recognise the influence of multiple factors, including biological, psychological and social factors to human health. Thus, as advocated by Watson and McDaniel (2000), moving from an 'Either-Or' to 'Both-And' thinking i.e. moving away from thinking of symptoms as being either psychological or physical to thinking of symptoms as both physical and psychological may be helpful in facilitating the development of a shared understanding between people who may come to the medical encounter with different understandings.

4.1.3   Management & Outcome

Psychotherapy is viewed as the treatment of choice for NEAD (Lesser, 2003), although Reuber (2009) highlighted that with increasing evidence to a possible biological vulnerability to NEAD (Bakvis, et al., 2009), this work may also enable better targeted medical interventions to be developed in the future. Despite some research pointing to the effectiveness of an individualised, eclectic team approach (LaFrance & Devinsky, 2002) that considers the multi-factorial understanding of NEAD and more recent research pointing specifically to the effectiveness of cognitive

behavioural therapy (CBT) for individuals with NEAD (Goldstein, et al., 2010), outcomes are generally poor for individuals, with considerable personal, social and economic implications (Gaynor, Cock, & Agrawal, 2009; Reuber, Pukrop, Bauer, Tessendorf, & Elger, 2003). O'Sullivan, Sweeny, & McNamara (2006) identified that one of the possible reasons for the relatively poor outcome in this condition may relate to confusion regarding the diagnosis among medical professionals. In particular, they surveyed GPs and found that many admitted to a poor level of understanding of NEAD. A similar lack of understanding has been identified amongst physicians (Shneker & Elliott, 2008) and therapists (Quinn, Schofield, & Middleton, 2010).

4.1.4   The individual's experience of living with NEAD

Qualitative studies have highlighted that many individuals with NEAD express that it is a confusing diagnosis to understand (Carton, Thompson, & Duncan, 2003; Dickinson, Looper & Groleau, 2011; Karterud, Knizek, & Nakken, 2010; Thompson, Isaac, Rowse, Tooth & Reuber, 2009). Carton et al. (2003) found that this reaction had a negative impact on prognosis and Dickinson et al. (2011) concluded that establishing a personal explanation for their condition helped individuals to find meaning in their experiences and a pathway to recovery.

Studies have found that anger and relief are also common feelings expressed by individuals following the diagnosis (Carton et al., 2003; Ettinger, Devinsky, Weisbrot, Ramakrishna & Goyal, 1999; Thompson et al., 2009), in addition to feelings of isolation and a perception that the reality of the illness is doubted by medical professionals, society, family and friends (Thompson et al., 2009). Finally, Thompson et al. (2009) found that many individuals reported feeling "left in limbo land" after their diagnosis with little support from the medical profession.

4.1.5   NEAD and the link to other 'contested conditions'

As reflected in the literature, NEAD remains a challenging condition for health professionals and individuals alike to understand. Furthermore, it is a condition that has experienced a troubled and changing history, particularly in relation to the conflicting ways of defining and re-defining the condition. For example, over 15

different synonyms have been attached to the condition, including 'hysterical[2] seizures', 'pseudoseizures' and 'psychogenic seizures', to name but a few (Scull, 1997).

Similar to chronic fatigue syndrome (CFS) and other 'contested conditions', NEAD is a condition that has yet to be explained from a medical-biological point of view and thus can be perceived as sitting on the "fringe of established disease patterns" (Dekkers & Domburg, 2000, p.30) and outside the confines of medical legitimacy. Dekkers and Domburg (2000) described that NEAD may be perceived as a 'non-disease' in that it lacks one or more of the three elements needed to constitute a 'real' disease i.e. a natural cause; specific pathophysiological findings and specific clinical findings. Research with individuals with NEAD have highlighted that many perceive organic illnesses such as epilepsy, as being genuine, whilst illnesses which are considered psychological, such as NEAD are perceived as less genuine (Green, Payne & Barnitt, 2004). Linked with this, many individuals report feeling rejected by doctors and perceived as malingers, time-wasters and attention seekers (Green et al., 2004). This is similar to findings reported by individuals with other medically unexplained conditions who report feeling questioned or judged either as not being ill or suffering from an imaginary illness (Werner, Isaksen & Malterud, 2004). In addition to this perceived skepticism and dissension, there is evidence that medical practitioners perceive people with contested conditions as possessing negative qualities, such as illness-fixation and pessimism (Asbring & Narvanen, 2003) and that people with conditions, such as CFS are, to some degree, contributors to their disability as a result of personality or behaviours (White & Schweitzer, 2000).

Within this context of de-legitimisation, where discourses surrounding the 'reality' of conditions prevail, it is no wonder that many individuals with NEAD report feeling offended when their symptoms are given labels that suggest a psychological origin for their symptoms (Carton et al., 2003). Research has suggested that such discourses can

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[2] Connected to the historical concept of hysteria which understood symptoms are being caused by the "wandering womb, which, being frustrated by lack of proper use, leaves its anatomical position and travels around the body causing pressure in anomalous places and hence symptoms" (Trimble, 2010, p. 17).

significantly influence illness experiences and alter self-perceptions (Travers & Lawler, 2008) for individuals with the conditions. For example, researchers have reported a disrupted sense of identity and competence (Gray & Fossey, 2003), a loss of self (Edwards, Thompson & Blair, 2007) and low levels of self-esteem among people with CFS (White & Schweitzer, 2000); as well as feelings of shame and guilt among individuals with other medically unexplained symptoms (MUS), which subsequently threaten their sense of self and social identity (Nettleton, 2006). As a consequence of feeling that they have no permission to be ill, in the absence of an accepted abnormal pathology, research has highlighted that many individuals with medically unexplained conditions report feeling pressured to constantly account for themselves (Nettleton, 2006) and construct their stories in order to convince their audience that their illness is somatic rather than imagined (Werner, et al., 2004).

In addition to discourses surrounding the perceived 'reality' of 'contested' conditions, such as NEAD, Dekkers and Domburg (2000) highlighted that "the medical attitude towards NEAD often appears reserved, reminding us of the misconceptions that surrounded epilepsy in the past" (p. 29) and argued that "today, NEAD sufferers carry the same stigma that sufferers with epilepsy carried in former times" (p.30). For example, they argued that with no glimpse of a clearly classifiable 'real' disease, the stigma surrounding the idea that the seizures are a consequence of the influence by a strange power remains unabated.

The concepts of felt and enacted stigma (Scambler & Hopkins, 1986) are well established in epilepsy research and research has suggested that the perception of a stigma surrounding epilepsy is rarely triggered by an enacted incident of stigma in society, with the general public being relatively well informed of epilepsy (Jacoby, Gorry, Gamble & Baker, 2004). In an attempt to avoid potential enacted stigma i.e. the negative reactions of others, Scambler and Hopkins (1986) posited that many people with epilepsy conceal their condition in order to pass as "normal". In turn, they highlighted that such an approach typically leads to fewer occurrences of enacted stigma, thus confirming the efficacy of such concealment to the person with epilepsy and the belief that there is something to be hidden or that their illness is undesirable. A

recent qualitative study exploring the experiences of stigma for adults with epilepsy highlighted that concealment of the condition remains common in today's society (Kilinc & Campbell, 2009). The study also highlighted other strategies that individuals used to manage their experiences of stigma, including frequent attempts to withdraw from society and avoid social interactions due to the embarrassment and fear of having a seizure in public and a gradual decision to selectively divulge the diagnosis to people that they trust. Whilst there have been no qualitative studies exploring the experiences of stigma in people with NEAD, it is likely that some of the findings from this study may be relevant to those living with NEAD in today's society and highlight the importance of remaining mindful of these issues when listening to narratives about NEAD.

4.1.6   Summary

With research suggesting that many individuals in Western society struggle to make sense of NEAD, this study is interested in how family caregivers of adults diagnosed with NEAD make sense of their experiences and narrate them. As the literature search revealed a scarcity of research on the meaning making and experiences of family caregivers of adults diagnosed with NEAD, I will begin by reviewing the literature on family experiences in other areas of illness in the following section, in particular in relation to chronic illness and medically unexplained symptoms; or, as Launer (2009) described, conditions which are medically unexplored stories. A review of literature within the areas of chronic illness and MUS was felt appropriate as NEAD is a condition that is often chronic in nature (Mellers, 2005) and is connected to the landscape of MUS (Hamilton, Martin, Stone, & Worley, 2010), beginning with the fact that the majority of individuals with NEAD receive the diagnosis of conversion disorder (Marchetti, et al., 2008).

4.2 Family Experiences and Chronic Illness

"The study of illness meanings is not only about one particular individual's experience; it is also very much about social networks.... An inquiry into the meanings of illness is a journey into relationships"

(Kleinman, 1988, p.186)

As Kleinman's quote suggests, illness does not solely affect the individual diagnosed with the condition but also has implications on those in a relationship with the individual; hence the impetus for this thesis. It is only in the last 40 years that empirical literature has began to focus on the relationship between families and illness (Jacobs, 1992) and I will briefly discuss the prevailing ideas from this literature.

4.2.1 Historical and prevailing views of families and chronic illness

4.2.1.1 *Family Pathology Model*

In the 1960s-70s, the family pathology model understood illness as existing because of dysfunctional family patterns. It was based on Minuchin's typology for the family, where factors such as poor conflict resolution, weak interpersonal boundaries and excessive over involvement or 'enmeshment' of family members were believed to be central contributors to the development of many chronic medical disorders (Minuchin, Rosman, & Baker, 1978). However, many researchers challenged this idea and in particular, Coyne and Anderson (1988) stated that this view "has, at times, led to an adversarial view of families of patients with chronic health problems" (p.122).

4.2.1.2 *Family Coping Model*

Since then, research has focused less on the role of the family in the development of physical health problems and more on the role of certain family attitudes and behaviours influencing the course of disorders (Brown, Birley & Wing, 1972; Vaughn & Leff, 1976). For example, within the field of MUS, the solicitous behaviour of spouses (including behaviours such as encouraging rest, taking over tasks and focusing on expressions of illness-related symptoms) have been found to be associated

with increased levels of symptom severity (Block, Kremer, & Gaylor, 1980; Flor, Kerns & Turk, 1987), poorer functional outcomes (Romano, et al., 1995) and lower activity levels (Flor, Kerns & Turk, 1987) in those with the condition.

These findings have led to an interest in the ways that families cope with the stress of chronic illness (Jacobs, 1992). One such model that focuses on the family response to illness is 'The Family Adjustment and Adaptation Response Model' (FAAR) (Patterson, 2002). This emphasises the active and continuous process that families engage in to balance family demands (stressors, strains, daily hassles) with family capabilities (resources and coping behaviours), as these interact with family meanings to arrive at a level of family adjustment and adaptation.

Although the family coping model has, as Jacobs (1992) argued "constituted a major advance over the more restrictive family pathology approach" (p.113), it has the potential to continue to situate family members in positions where they may be blamed for the maintenance of the illness and does not directly consider the impact of illness on the family and their subjective experiences.

4.2.1.3 *Impact of Chronic Illness on the Family*

Following on from this, a significant amount of literature has focused on the family as "potential causalities of the illness process" (Jacobs, 1992, p.113).

4.2.1.3.1 *Quantitative literature*

Within the context of MUS, quantitative studies have mainly focused on the impact on spouse caregivers. Studies have indicated that spouses of adults with MUS report low mood (Bigatti & Cronan, 2002; Flor, Turk & Scholz, 1987; Rowat & Knafl, 1985), physical symptoms (Rowat & Knafl, 1985) and sleep problems (Goodwin, 2000). Spouses of individuals with MUS have also reported changes in roles and responsibilities within the home (Steiner, Bigatti, Hernandez, Lydon-Lam & Johnston, 2010), financial difficulties due to the loss of employment (Goodwin, 2000) and strains in marital relationships, with many spouses reporting marital dissatisfaction (Steiner et al., 2010). In particular Flor, Kerns and Turk (1987) found that marital

dissatisfaction was more prevalent in female spouses, although a more recent study by Flor, Turk and Rudy (1989) did not support this finding.

A key limitation of such quantitative studies, however, is that it is often unclear whether factors, such as marital dissatisfaction started before or after the onset of the illness due to their cross-sectional design and longitudinal studies are therefore required to address this limitation. Furthermore, self-report questionnaires have also been criticised for representing a decontextualised approach to caregiving due to their difficulties in exploring the complex life experiences that carers and individuals face in their day-to-day lives (Ayres, 2000). Qualitative research may offer an alternative lens to gain a more in depth understanding of the experiences of caregivers.

4.2.1.3.2 *Qualitative literature*

The comparatively few qualitative studies within the field of MUS provide further insights into the complex and multiple experiences of spouses. Common themes arising from this literature include the insights that many spouses feel like they are 'living in the shadow' of the illness (Paulson, Norberg, & Soderberg, 2003; Soderberg, Strand, Haapala & Lundman, 2003) and leading restricted lives (Paulson et al., 2003; Soderberg et al., 2003). Paulson et al. (2003) also found that the illness was perceived by some spouses as being a 'forceful third member of the relationship' and highlighted, along with other qualitative studies (Fernandez, Reid, & Dziurawiec, 2006; Soderberg et al., 2003), the complex disruption that illness can have on relationships. However, in these studies, some spouses also spoke of the illness leading to a growth in their relationship with their partner. Furthermore, many spouses of adults with fibromyalgia reported a perception that other people did not understand the condition, which often left them feeling isolated, and spoke of their need to advocate for their partner in the struggle to get fibromyalgia accepted as an illness by friends and the wider society (Paulson et al., 2003; Soderberg et al., 2003). They also spoke of lacking in information and knowledge about the condition and having to seek this out for themselves (Paulson et al., 2003; Soderberg et al., 2003).

Whilst this research has contributed significantly towards providing further insight into the subjective experiences and meanings of caregivers of adults with MUS, it predominantly focuses on the experience of spouses and there is a paucity of research on the experiences of parent caregivers of adults with MUS. In comparison, qualitative research focusing on parents as caregivers for adult children diagnosed with a mental health condition or a learning disability have highlighted a number of pertinent themes, all pointing to the possibility that parent caregivers and spouse caregivers may experience certain aspects of their caregiving roles in different ways. For example, Tuck, du Mont, Evans, and Shupe (1997) found that parents experienced the diagnosis of schizophrenia that their adult son or daughter received as a destructive force that transformed the family life trajectory and they experienced parenting as being unending. Furthermore, Ferriter and Huband (2003) and Pejlert (2001) found that parents of adult children diagnosed with schizophrenia often blamed themselves for the disorder. However, similar to the literature on spouse caregivers, research has also pointed to the positive experiences or the 'rewards and gratifications' reported by parents caring for their adult children (Grant, Ramcharan, McGarth, Nolan, & Keady, 1998).

4.2.1.4 *Summary of historical and prevailing views of families and chronic illness*

In this section, I have highlighted how understandings have transitioned from viewing family members as contributing to the development and course of an illness, to considering the influence of the illness on family members. Whilst the latter studies have highlighted a particularly important point, namely, that caring for a spouse or adult son or daughter with a chronic illness or medically unexplained condition can have significant emotional, physical and lifestyle consequences, they mainly focused on *what* participants said and little attention was paid to *how* they talked about events and what contextual factors may have influenced the meanings and the stories they told. In comparison, interest in narrative, and its role in meaning-making and 'identity work' (Hyden, 1997) has grown and provides an alternative approach to exploring the stories about illness by considering the contextual factors influencing the stories told. I will briefly consider the work on illness and narrative in the next section.

4.2.2 Factors influencing family meaning making within the context of chronic illness

Empirical research in the field of sociology has contributed significantly towards formulations about the (chronic) illness experience and has underlined the importance of locating and understanding experience of illness within a diverse range of "macro [social] and micro [familial & other interpersonal relationships] contextual factors" (Lawton, 2003, p. 27).

4.2.2.1 *Conceptual understandings of chronic illness*

Bury's sociological formulation of the notion of chronic illness as a 'biographical disruption' (Bury, 1982) has been particularly influential in contributing towards an understanding of chronic illness. In particular, he theorised that the onset of an illness disrupts assumptions and behaviours, explanatory systems and mobilisation of resources and results in a marked biographical shift from the perceived normal trajectory of life (Bury, 1982). Closely linked to this, G. Williams (1984) spoke of rheumatoid arthritis as being an "assault on an individual's sense of identity" (p.175) and pioneered the notion of 'narrative reconstruction' to describe the conceptual strategies that individuals employ in an "attempt to reconstitute and repair ruptures between body, self and world by linking-up and interpreting different aspects of biography in order to realign present and past and self with society" (p.197).

Since this research, evidence has expanded to include other biographical concepts, including the concept that the onset of illness may be viewed more as a 'biographically anticipated' event (S. Williams, 2000) rather than a disruptive event, particular when illness is viewed as being part of a 'normal' process of ageing (Pound, Gompertz, & Ebrahim, 1998). Challenging the implicit assumption of Bury's theory that illness always enters lives that have not previously encountered crises or struggles in the past (Lawton, 2003), the concept of illness as a form of 'biographical reinforcement' or 'biographical continuity' has also been proposed, particularly where individuals have previously organised their lives and biographies around an illness trajectory (Carricaburu & Pierret, 1995). Furthermore, Asbring (2001) has proposed that disruption may be partial and only occur in certain areas of life, such as work and

social identities and can bring positive or 'illness gains' such as changed values, insights into 'self' and increased understanding of illness. Finally, Sanderson, Calnan, Morris, Richards and Hewlett (2011) proposed the concept of 'shifting normalities' to provide a dynamic explanatory model of chronic illness that captures the interaction of changing conceptions of a normal life and the normalisation of symptoms.

4.2.2.2 *Caregiving & biographical disruption and reconstruction*

Whilst the biographical literature has focused mainly on first-person accounts of chronic illness, some studies have applied these concepts to understanding how the caregiving 'self' is narrated and experienced within the context of physical and mental illness and across different cultures (e.g. Adamson & Donovan, 2005; Chamberlayne & King, 1997; Harden, 2005; Owens, Lambert, Lloyd & Donovan, 2008; Ramsay, 2010). For, as Chamberlayne and King (1997) wrote, carers could be said to "share the moral world of the chronically ill" (p.602). Furthermore, Denzin (1989) argued that the encounter with caring and disability is often equivalent to a "turning point in the biography" (p.23), which significantly shapes the carer's life and, as Pierret (2003) wrote, may lead to a "quest for meaning" (p.8) in an attempt to make sense of the illness within the context of their lives.

These studies have highlighted that for some carers, the experience of caring is seen as an accepted part of their biography and may be coped with through a strategy of 'biographical continuity', by integrating caring and disability into some pre-existing biographical form. In comparison, for others, caregiving appeared to involve significant biographical change and was considered as a highly disruptive event, leading to a loss of former life plans and identities, transitions in their relationships and perspectives for the future (Adamson & Donovan, 2005; Chamberlayne & King, 1997). Similar to Rolland (1987) who considered the different impacts that illness may have on a family depending on what stage they are in the family life cycle[3], this research points to the importance of considering the life-stage of the individual carer and the carer's whole biography when understanding their experiences of caregiving.

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[3] It is noteworthy that Rolland's model has been criticised due to its Western focus and the fact that it doesn't account for differing cultural factors in relation to the family life cycle and key life cycle transitions (McGoldrick, 1992).

These studies have also indicated the importance of contextualising the experiences of carers within the wider societal context. For example, Adamson and Donovan (2005) suggested that carers' accounts could be understood within the wider context of caring, with many carers portraying caring as a virtuous state. Furthermore, Harden (2005) suggested that the meanings given by the parents in their study who were caring for a young person with a mental health problem must be contextualised in terms of wider understandings of parenting and in particular, ideas around parental responsibility and the transition into adulthood. Finally, by locating culture at the centre of their analysis, Ramsay (2010) found that severe mental illness constituted a disruptive event for mainland Chinese caregivers who, despite the normative cultural expectation for family caregiving, actively concealed the family member's condition to protect the family, in light of the intense stigma surrounding mental illness in Chinese culture.

4.2.2.3 *Importance of considering family meaning making*

How individuals construe their experiences and re-create meaning is likely to impact on their attitude and behavior towards the condition (Canzoneri, 2010) and can have significant implications for long-term physical and emotional well-being. Nolan, Grant, and Ellis (1990), for example, suggested that meaning plays a significant role in caregivers' affective responses to caregiving. Furthermore, Stern et al. (1999) found a connection between the meanings that family caregivers constructed about their experiences of caring for a relative diagnosed with serious mental illness and the types of coping strategies they spoke about.

For example, Stern et al. (1999) found that all carers began with a description of the disruption implicated by the experience of illness. However, some told stories (identified by the authors as being stories of 'restitution' or 'reparation') which suggested that over time, the carer had engaged in a process of searching for a platform upon which to reconstruct a sense of personal 'identity'; a process that they suggested was still continuing. They hypothesised that finding this platform helped carers to "locate the illness and view its consequences in their map of the world" (p.5). They suggested that it functioned much like "'narrative scaffolding', out of which the

'abyss' of illness could begin to be contemplated" (p.5). In comparison, others told stories (identified as 'chaotic' or 'frozen' stories) where the illness appeared to remain a series of random events and the carers seemed unable to break loose from a repetitive way of telling, inhibiting the movement from disruption to platform to reconstruction.

They found that in the latter stories, it was more difficult to identify coping strategies because the story remained stuck at the point of disruption, whilst for the stories of 'restitution', more useful coping strategies were identified in their stories. Whilst their sample size was limited, their study offers some interesting insights into the concepts of disruption and reconstruction in family caregivers. Furthermore, it highlights the importance of developing an insight into the family's theory, thoughts and feelings about the nature of problems, which often serves the basis for social constructionist therapies, whereby therapists help the individual or family member to expand their story to allow for new and hopefully more helpful stories to develop (White & Epston, 1990).

4.2.2.4 Summary

This research has highlighted that the onset of an illness is likely to have differing impacts on how family caregivers story their 'selves' and their experiences, depending on factors relating to their biography, gender, age and the context in which they live. It has also pointed to the importance of considering the meanings that caregivers make about their experiences, to inform possible therapeutic interventions. As the literature search has identified no studies exploring the meanings told by family caregivers of individuals with NEAD, this research suggests the importance of studying their meanings, whilst also considering contextual factors that may influence this process.

Before discussing the research aims, I will briefly review the literature in the following section that includes family members of individuals with NEAD.

4.3   Family studies and NEAD

Relatively few studies have extended their focus beyond the individual to the wider social and family context in relation to NEAD. The studies that have been published have primarily focused on the role of family functioning in NEAD and although limited, have pointed to a reciprocal relationship between 'dysfunctional' family functioning ('disturbed' family system relationships) and NEAD (Archambault & Ryan, 2010). I will briefly discuss the findings from these studies, before exploring the gaps in the literature.

4.3.1   Studies on family functioning

The current research on NEAD and family functioning have revealed that individuals with NEAD, as compared with those with epilepsy, report significantly more marital and family problems (Roy, 1989, as cited in Moore et al., 1994), perceive their families as more controlling (Salmon, Al-Marzooqi, Baker & Reilly, 2003) and less supportive (Moore et al., 1994) and perceive conflicts in how family members verbally express feelings and show interest and concern for one another (Krawetz et al., 2001). La France et al. (2011) reported similar findings but found that male participants in both the NEAD and epilepsy group reported greater family dysfunction than female participants, suggesting that seizures may affect males' perceptions of the family in a different manner than women.

The limited research on the family members of individuals with NEAD have found that compared with family members of those with epilepsy, they report significantly more health problems, perceived criticism and marginally more distress and somatisation (Wood, McDaniel, Burchfiel & Erba, 1998), are more critical, hostile and emotionally over-involved (Stanhope, Goldstein & Kuipers, 2003) and report significantly more difficulties in defining roles within the family (Krawetz et al., 2001), suggesting that the caregiving role may impact on their sense of 'identity'. However, in this latter study, the responses of the family members did not differ in regard to the role they assumed within the family unit (i.e. spouse, parent).

Although acknowledging the limitations of their research, these findings have led authors to conclude that families may unwittingly contribute to the development of NEAD in a family member because of their characteristic adaptation to distress, such as through severe patterns of somatisation (Wood et al., 1998); and that non-epileptic seizures may represent a method of nonverbal communication to enable individuals to convey their sense of distress, in an environment where verbal communication may be discouraged (Krawetz et al., 2001). Furthermore, Stanhope, Goldstein and Kuipers (2003) hypothesised that the higher emotional over-involvement found in their study in family members of individuals with NEAD may have reflected their concern about a condition with no obvious cause and uncertain prognosis.

4.3.2 Limitations

Although these studies have made an important contribution to the literature on NEAD, they are limited by small sample sizes and heterogeneous samples and typically recruited their samples through tertiary epilepsy units, thereby limiting the ability to generalise the findings to those managed in the community. Furthermore, the cross sectional nature of the studies leave open the question of causality i.e. whether the reported difficulties preceded or were as a consequence of the impact of NEAD on the family. Prospective and longitudinal studies in this area are therefore needed to explore this issue further.

Finally, this research relies heavily on data collected through self-report questionnaires and employs a quantitative methodology from a positivist framework. Thus, its aim is to predict and explain human behaviour by focusing on causal relationships between supposedly objective variables (Murray, 1997). In contrast, a postmodernist framework would argue that family functioning cannot be explained or predicted by objective bodies of knowledge and would argue that viewing families through the lens of standardised assessments leads to a de-contextualised perspective on families (Banyard & Miller, 1998) and to 'expert' researchers defining a family's reality for them, thus offering limited room for change or possibility (Canzoneri, 2010). Finally, I would argue that, similar to a deficits based model of functioning, such an emphasis on a search for a causal relationship between family factors and

NEAD may invite family members to be perceived in terms of dysfunction and in a negative light, with a great deal of explicit and implicit blaming directed their way.

4.3.3 Gaps in the literature

In summary, the studies to date have pointed to a reciprocal relationship between family functioning and NEAD. Similar to the family pathology model that I discussed in the previous section, they serve to situate family members in positions where they may be implicitly blamed for the onset and maintenance of the condition and do not directly consider the impact of the condition on the family. Unlike in other areas of chronic illness, there are currently no quantitative or qualitative studies that focus directly on the experiences of NEAD for the family caregiver, despite scholars in the field highlighting a need for research to explore their views (Goldstein & Cull, 1997). However, there is some suggestion in the literature that family members may be anxious or angry about the diagnosis (Reuber & House, 2002) or may react negatively to the diagnosis, by either refusing to accept it or insisting that the individual has been 'putting it on all along' (Scheepers, Budd, Curry, Gregory, & Elson, 1994). Furthermore, research suggests that family members of women with NEAD may be more likely to accept a psychological explanation for seizures than family members of men with NEAD (Oto, Conway, McGonigal, Russell & Duncan, 2005), possibly since functional symptoms are more prevalent in women or are seen by many as more socio-culturally sanctioned in terms of traditional gender stereotypes.

Thus, this research points to the possible challenges that caregivers may face in making sense of NEAD and to the need for further research. Furthermore, whilst it is promising that a number of researchers are advocating for the use of family therapy in the management of NEAD (Archambault & Ryan, 2010; LaFrance & Barry, 2005; LaFrance et al., 2011), this is primarily based on research that points to a deficits based understanding of family members and there is clearly a need for greater understandings about the nature of the experiences of family caregivers supporting adults diagnosed with NEAD in order to inform the development of treatment and enhance understanding of professionals working with this client group.

4.4 <u>Research aims and questions</u>

In line with the gaps in the research literature, this study aims to address some of these limitations by focusing on the stories told by family caregivers of adults diagnosed with NEAD about their experiences. A further aim is to move beyond the level of the individual story to "the storied landscapes" (Clandinin & Connelly, 2000, p.24) and to consider the wider social contexts that may influence their experiences.

With these aims in mind, the main research questions for this study are:

1. *What is the content of the stories told by family caregivers of adults diagnosed with NEAD about their experiences?*

2. *How are these stories told?*

5 Methodology

"If we understand the world narratively...., then it makes sense to study the world narratively" (Clandinin & Connelly, 2000, p.17)

This section aims to locate the reader within the methodological landscape of the study. I hope to provide the reader with a transparent account of the research process and discuss aspects relating to the 'quality' and ethics of the research, participant recruitment and the composition of research texts[4].

5.1 Qualitative Methodology

A qualitative approach was chosen for this study as no such studies have yet been conducted with family caregivers of adults diagnosed with NEAD and qualitative approaches are known to enrich current understandings, particularly in under-researched areas (Barker et al., 2008).

A number of qualitative approaches were considered for the study, including grounded theory, interpretative phenomenological analysis, discourse analysis and narrative inquiry. Whilst any of these would have been able to shed light on the caregivers' stories, I chose a method situated within the traditions of narrative inquiry and social constructionism.

5.2 Narrative Inquiry

5.2.1 The case for narrative inquiry

Narrative inquiry was chosen as the methodology for several reasons.

Firstly, it is viewed by many researchers as being the most appropriate methodology to explore meaning and experience (Clandinin & Connelly, 2000; Smith & Sparkes, 2009). It has also been used in other areas of health to explore how individuals with

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[4] I refer the reader back to my introduction for a discussion of the epistemological framework underpinning this thesis and my personal motivations for completing the research.

chronic illness attempt to deal with their life situations and the problems of 'identity' that illness may bring with it (Kleinman, 1988; Murray, 1997; Overcash, 2003). Finally, it is viewed as a useful qualitative methodology, particular where the focus of enquiry is upon the relationship between 'self' and culture (Weatherhead, 2011). In line with the aims of the study, I decided that narrative inquiry would therefore provide a suitable framework to meet these aims.

5.2.2 Definitions of narrative analysis

Narrative analysis takes as its focus of investigation the story itself and is concerned with retrospective meaning making (Riessman, 1993). Within the literature, there are many definitions of narrative, in addition to many disagreements about the definitions (Riessman, 1993). For the purposes of this thesis, I have chosen to adopt a broad definition of narrative. Firstly, I have drawn on Squire's (2008) perspective that narratives are "sequential and meaningful", relate to human experience and re-present experience (p.42). I have also drawn on elements of Riessman's (2008) perspective that, in the process of storytelling, events perceived by the narrator are "evaluated as meaningful for a particular audience" and in terms of the meanings that the narrator "wants listeners to take away from the story" (p.3).

Thus, I approach stories from the premise that narratives or stories are a way in which individuals make sense of themselves and the world (Bruner, 1990; Squire, 2008) and constitute individuals' efforts to restore violations of normality (Bruner, 1990). Linked to this, I understand that individuals construct their 'identities' through the act of storying (Arvay, 1999, as cited in Hole, 2007). Finally, I understand that stories are constructed between people, are produced for specific audiences[5] and are context dependent. I share Riessman's (1993) view that narratives "do not mirror the world out there" (p.5) or pre-exist but rather "are constructed, creatively authored [and] rhetorically replete with assumptions" (p.5).

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[5] Which may include both the immediate listener and those who might overhear the conversation, or read the research (Elliot, 2006)

Whilst 'narrative' is often used interchangeably with the term 'story' in the literature on narrative research, I consider them to have different meanings in this thesis. I have drawn on Polkinghorne's (1988) understanding of 'narrative' to differentiate the terms; that is, he defines narrative as involving "stories, it is more than a single story" (p.35) and which embraces the "collective 'stored wisdom' of people's individual stories" (p.35). Therefore, for the purposes of this thesis, the word 'narrative' is used to refer to a set of stories, whilst the word 'story' refers to a single story that focuses on a particular theme.

5.3 'Quality' of the study

'Quality' refers to the question of why readers should believe research (Riessman, 2008). Whilst a number of qualitative scholars, including Lincoln and Guba (1985) have offered important insights about best practices for qualitative research, many researchers, particularly from the narrative tradition, have argued that there can be no formal rules for validation as "values of 'quality', like all social knowledge, are ever changing and situated within local contexts and current conversations" (Tracy, 2010, p.837). Riessman (2008) wrote that approaches to validity depend ultimately on one's epistemological position. In keeping with my social constructionist position, I was particularly influenced by writings by Tracy (2010), who attends to the contextual, rather than the 'true' nature of 'quality'.

I therefore chose to draw from her 'Eight Big-tent criteria' (2010) in considering the 'quality' of my research, where she recommended focusing on the following aspects of the research: worthy topic, significant contribution, meaningful coherence, rich rigor, sincerity, credibility, resonance and ethics. For a discussion of the first three 'quality' criteria, I orientate the reader to the introduction chapter and summary of the findings chapter. In relation to the remainder of Tracy's 'quality' criteria, I will subsequently endeavour to refer to these throughout this chapter. In particular, my attempt to provide the reader with a transparent account of the research process is connected to one of the markers indicated by Tracy (2010) that she defined as 'sincerity'. She described that this word relates to "notions of authenticity and

genuineness", which can be achieved by research being "marked with honesty and transparency" about the research process (p.841).

5.4   Ethical considerations

Ethical considerations were identified by Tracy (2010) as a key marker to ensure good 'quality' qualitative research and prior to entering the field and starting my research, I was guided by the British Psychological Society Code of Ethical Practice (BPS, 2004) in considering the ethical decisions that I would adhere to throughout my study, including informed consent, confidentiality and participant wellbeing.

Prior to commencing the study, ethical approval was also obtained from The University of Hertfordshire Advisory Committee on Ethics (Appendix B) and I was advised that NHS Ethical Approval was not required (Appendix C). The charity from which I recruited agreed that appropriate ethical approval had been sought (Appendix D) and no further action was required. Some minor amendments were approved by The University of Hertfordshire Ethics Committee at a later date (Appendix E) to permit minor changes[6] to the participant selection criteria.

5.4.1   Informed consent

All potential participants were provided with a copy of the Information Sheet (Appendix F) which explained the aims of the research and requirements for participation. The nature of the research as being part of a formal qualification was also outlined, in addition to the voluntary nature of participation.

Whilst I was mindful of the complexity of gaining informed consent for more unstructured, narrative interviews and research questions (Elliott, 2006), this information and the time given to participants to ask questions aimed to provide them with sufficient information to make an informed decision about their participation.

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[6] These included broadening the initial criteria to include caregiver friends and allowing for participants whose family member/friend did not have a definitive diagnosis of NEAD but whose Consultant understood NEAD as being the most likely understanding for their seizures. These changes followed from conversations with members at the NEAD Trust Conference in April 2010; the charity that I recruited from.

Participants were informed about their right to withdraw at any time and were asked to sign a Consent Form (Appendix G).

5.4.2 Confidentiality

In the Information Sheet and throughout the process, participants were assured that their personal information would remain confidential, be stored securely on password protected computers and would only be accessible to myself and my research supervisor. They were also informed that extracts from the interviews may be used in the write-up of the study but that any identifying material would be omitted and that they would be allocated a pseudonym in order to attempt to maintain anonymity and confidentiality. Due to the possibility that their stories may be recognisable to those familiar with their experiences (Elliott, 2006), this issue was discussed with participants at the outset to ensure they could make an informed decision about their participation.

5.4.3 Participant well-being

Due to the personal and potentially sensitive nature of the topic, the importance of protecting the well-being of participants remained paramount throughout every stage of the research. Thus, prior to consenting, I discussed with participants about the potential that the interview may elicit unexpected distress, in addition to the possibility that they may experience the process as therapeutic. During the interviews, I also checked that participants were happy to continue if they became distressed and used my clinical skills to support them both during and after the interview. Participants were reminded of their right to withdraw at any time and were given time at the end of the interview to share their thoughts about the interview process. A Debrief Sheet (Appendix H) was also given to all participants that included details of helping agencies and my contact details so that they could discuss any issues after the interview if they wished to.

5.5   Entering the field: sampling and recruitment of participants

5.5.1   Sample

Ten caregivers[7] were purposively recruited for the study. Whilst this was a small sample, Weatherhead (2011) argued that a small number of participants are appropriate for narrative studies. The selection criteria were kept relatively broad due to the aim of collecting data reflecting a variety of experiences. Participants were required to be over the age of 18 and be supporting an adult family member or friend with a diagnosis of NEAD or whose seizures were understood as being non-epileptic in nature. It was required that this diagnosis or understanding followed the exclusion of a diagnosis of epilepsy or other possible neurological or physical causes for the basis of their seizures, by a consultant neurologist or other appropriate medical professionals over recent years.

5.5.2   Recruitment of participants

All participants were recruited from an online charity organisation called NEAD Trust which has an online forum for individuals with NEAD and their families and organises a monthly support group in Sheffield. The organisation was primarily selected as I wanted to engage with caregivers of individuals who were living in the community.

The recruitment process followed a number of stages including handing out a letter explaining the research (Appendix I) at a conference run by NEAD Trust, advertising the research on the NEAD Trust online forum (Appendix J) and NEAD Trust Facebook page (Appendix K) and emailing the advertisement to all of the members of NEAD Trust. This resulted in 28 caregivers contacting me via email to express an interest in the research. The Information Sheet outlining the study was sent electronically to provide them with further details and following this, interviews were arranged with four caregivers who met the criteria for the study.

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[7] A brief description of the participants can be found in the beginning of the findings section

In an attempt to recruit further participants, a follow up email (Appendix L) was sent to those who had initially expressed an interest in the research and a follow-up advertisement was posted on NEAD Trust Facebook page (Appendix M). This resulted in a further six participants contacting me to arrange an interview. As such, a total of ten interviews took place over a four month period. The Consent Form was emailed to all participants to read, sign and bring to the interview.

The table below provides a summary of the recruitment process:

Recruitment steps	Number who expressed an interest	Number who met for interview
Conference	2	1
1st advert on NEAD Trust website	1	1
2nd advert on NEAD Trust Facebook page & via email to all members	25	2
Follow up email to those who expressed an interest	6	6
Total	*34*	*10*

Table 1: Summary of the recruitment process

5.6 Creating field texts and moving to research texts: Walking in the midst of stories

In narrative research, 'field texts' refer to the types of information (or 'data') that researchers collect from the research 'field'. In this section, I hope to take the reader through the different stages of my research process from composing and creating field texts, to creating research texts. Through this process, I hope to reflect my understanding that I can never have direct access to another's experience but that all

representations of experience are ambiguous, partial and co-constructed (Riessman, 2008). Furthermore, I hope to reflect my understanding that all research texts are contextually and temporally bound and that research always begins in the midst of stories (Clandinin & Connelly, 2000) and thus includes stories that are always evolving and changing.

5.6.1   Composing Field Texts

5.6.1.1 <u>Interview Structure</u>

The interview is a widely used method of creating field texts (De Fina, 2009; Mishler, 1986) and was the core method used in my study.

Based on my premise that narratives are co-constructed between individuals, I approached the interview from the perspective that I would be entering into a conversation (Riessman, 2008) with my participants and aimed to establish a climate that encouraged detailed story-telling. Guided by researchers such as Riessman (1993), I developed a broad interview guide (Appendix N) prior to the interview, drawing on some of the caregiving literature included in the literature review. As such, the interviews were loosely structured around a number of topics, including the carers understanding of NEAD, implications of caring on their lives and their experiences of support from healthcare services.

I began the interviews by asking participants how they came to be interested in volunteering for this research. I subsequently asked a broad opening question: '*Can you begin by telling me in your own words something about your experiences of supporting (name of individual) with NEAD, beginning at a place where you feel is most appropriate to start'* to encourage participants to begin telling their story. Following this, I used open-ended questions such as, '*I was interested in hear about (reference to the topic) and wondered if you can tell me a bit more about that'* to encourage more detailed story-telling and drew on my interview guide where appropriate to prompt stories relating to certain aspects of their experience.

5.6.1.2 Interview Process

All participants were interviewed on one occasion and the interviews typically lasted between 45 to 90 minutes. The interviews took place at a location that participants indicated was most convenient for them and as such, the location varied from rooms at local libraries, community centres or universities, to one home visit (relevant Home Visit guidelines were followed; please see Appendix O). Before the interview commenced, the Information Sheet and Consent Form were reviewed to clarify any questions. The unstructured nature of the interview was also discussed, as I anticipated that some participants may expect a more traditional semi-structured interview. Following this, participants were asked a more detailed set of screening questions that included questions about their age, name of the individual with NEAD whom they supported, the nature of their relationship and further details about the diagnosis, to provide a context for the conversations to follow.

All interviews were recorded and after the interviews and recordings were completed, time was given for participants to share their reflections and to de-brief. Finally, notes were taken following the interview to record my thoughts and reflections about the stories shared and the process of the interview.

5.6.2   Creating written field texts

In transforming the verbal accounts from the interviews into textual accounts, I recognised that this process in itself was a type of representation that involved selection and reduction (Riessman, 1993) and that the resulting transcript would be "incomplete, partial and selective" (Riessman, 1993, p.11). Thus, whilst I shared Kogan and Gale's (1997) view that all features of talk in the interview context contributed to the production of meaning, I spent time considering what level of transcription would be most appropriate for my research study. I decided that the production of transcripts at the level of words and dominant conversational characteristic was sufficient to attend to the stories told by the participants. Thus, I focused on the participant's and interview's words, other dominant features of the conversation and expressions of emotion i.e. pauses, laughs, crying, sighing and nonlexical expressions (e.g. Mmm, uh).

I subsequently transcribed the first three interviews and due to time limitations, the remaining seven were transcribed by a professional transcription service who signed a confidentiality agreement prior to transcription (Appendix P). In the case of an interview being transcribed by a professional typist, I ensured that I listened to the interviews and amended necessary details.

5.6.3   From Field Texts to Research Texts

In developing my process of analysis, I was informed by the writings of Clandinin and Connelly (2000), Daly (2007), Emerson and Frosh (2004), Lieblich, Tuval-Mashiach, and Zilber (1998) and Riessman (1993; 2003; 2005; 2008). Thus, I did not follow any one single approach but drew on a variety of analyses in order to understand the texts in different ways; an approach advocated by Coffey and Atkinson (1996) who stated that the more we examine our data from different viewpoints, "the more we may reveal – or indeed construct – their complexity" (p.14).

Tracey (2010) highlighted that a study's 'rigor' may be achieved through providing the reader with a transparent account of the analysis process and in this section, I hope to address this by highlighting the process that I engaged in when transforming my field texts into research texts.

5.6.3.1 *Definition of narrative*

Rather than selecting discrete sections of text that met criteria for being 'storied', as some scholars have done (e.g. Labov, 1972, as cited in Riessman, 2008), I took the whole life story, as generated within the context of the research interview as the starting point for my analysis (Lieblich et al., 1998). In line with my approach to stories, I also included a focus on "the verbal interactions in interviews i.e. discrete narrative segments, or stories, and other utterances...that develop jointly with the audience/listener" (Riessman, 2003, p.26).

5.6.3.2 *Multiple Readings*

Based on my research questions, I was interested in both the content of the texts (i.e. what was said) and on the performative aspects of the texts (i.e. how the stories were

told and performed). The analysis followed a number of close and repeated readings of the written field texts and these were completed for each individual narrative, before looking across all of the narratives. To integrate the focus on both the *whats* and then the *hows* within the texts, I drew on Gubrium and Holstein (2000) process of analytic bracketing: "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).

Although the readings are presented as a single linear process, the analysis process itself involved an iterative process of moving between the different readings in a varied sequence. The analysis involved at least four readings of the written field texts. I have provided an example of the process of analysis for one participant in Appendix Q to aid transparency, along with the transcript of this interview in Appendix R.

5.6.3.2.1 *Reading for content*

Initially, to focus on the content of the text (i.e. "what" was said, Riessman, 2005), I was guided by and drew on elements from Lieblich et al's. (1998) 'Holistic-Content' perspective. These authors proposed that readings could follow a number of stages (pp. 62-63):

1. Read the material several times until a pattern emerges, usually in the form of foci of the entire story. Read or listen carefully, empathically, and with an open mind.

2. Put your initial and global impression of the case in writing.

3. Decide on special foci of content or themes that you want to follow in the story as it evolves from beginning to end.

4. Using coloured markers, mark the various themes in the story, reading separately and repeatedly for each one.

5. Follow each theme throughout the story and be aware of where a theme appears for the first and last times, the transition between themes, the context for each one, and their relative salience in the text.

Thus, I read each narrative for the different stories and then chose to group together stories with similar themes under thematic storylines[8]. My decision to consider the thematic organisation, as opposed to the chronological sequence of stories throughout each narrative corresponded to the nature of the accounts as participants did not recount events in a clear chronological order but told stories in a way that reflected the ongoing negotiations between us (De Fina, 2009). Such a thematic organisation also fitted with a post-modern attempt to resist a totalising interpretation that claims to be a singular version of the participant's lives and instead strives to present the complexity of their lives and the fluidity of their identities and multiple identities (Blumenreich, 2009).

5.6.3.2.2 *Reading for performance*

Secondly, to focus on the 'telling' and the way the stories were told (Riessman, 2005), I read each narrative to focus on relational and performative aspects of the storytelling. As indicated below, Riessman (2003, p.8) pointed to a number of questions that the researcher can ask themselves when reading texts:

1. In what kind of stories does the narrator place him/herself?

2. Why was the illness narrative developed that way, and told in that order?

3. How does the narrator strategically make preferred 'identity' claims? What other identities are performed or suggested?

4. What was the response of the listener/audience and how did it influence the development of the narrative, and interpretation of it?

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[8] This term will be used to refer to a group of stories that are thematically related and tell a story over time

When considering '*what kind of story*' or 'type' of story the participant appeared to be telling, I considered aspects such as plot development and language use across all the thematic storylines. In line with my premise that narratives and meanings are constructed in interaction with others, I also considered the possible influence of factors such as the power differential between myself and the participant and how my perceived age, culture and gender may have influenced the telling of the stories (De Fina, 2009).

5.6.3.2.3   Reading in context

Thirdly, in line with my premise that narratives and meanings are shaped by social, cultural and historical contexts, I read the text to consider the possible influence of these factors on the telling and asked myself the question: "how is this story situated in social, cultural or institutional discourses" (Daly, 2007, p.223).

5.6.3.2.4   Reading across narratives

Finally, after completing the analysis for individual narratives, I began to hold the narratives in relation to each other and noticed that whilst each participant told stories which differed to some extent, there also appeared to be common stories running throughout. Thus, in line with the multiple lenses that were employed when looking at the individual narratives, I compared and contrasted the narratives by considering elements of content and performance.

Whilst some scholars recommend, where appropriate, for researchers to adopt a comparative approach involving the interpretation of similarities and differences among participants' stories (Riessman, 2008), I was initially concerned that this may lose the richness and individuality of the narratives of experience. However, collective voices in the main precede individual voices in the dialogic perspective of narrative and narrative 'identity' (Smith & Sparkes, 2008) and thus, based on my premise that narratives are always co-constructed between people (including in the interview setting) and interlaced with discourses that define us (Burr, 2003), I felt that a focus on the collective thematic storylines was more fitting.

Furthermore, I hoped that this may enable a more comprehensive analysis of the contextual influences shaping the stories, and may, as Clandinin and Connelly (2000) argued "represent a more complete sense of the narrative of the inquiry field" (p.139). Finally, as the stories of carers of adults diagnosed with NEAD are relatively unheard within the research community, my decision to focus on the stories across all the interviews was also influenced by the literature within community psychology which focuses on the benefits of documenting communal stories to draw greater attention to the needs of communities (Banyard & Miller, 1998).

5.6.4 Composing Research Texts

Before presenting and discussing the findings of this research, I will briefly discuss the process of how I came to decide how to compose the research texts for this thesis, in an effort to make my choices and motivations clear to the reader. Furthermore, I aim to address two further 'quality' markers identified by Tracy (2010); credibility and resonance.

5.6.4.1 Decisions regarding the choice of narrative accounts to include in the research texts

Whilst I analysed all ten interviews, I have chosen to focus on the narratives told by only eight participants for this thesis, all of whom were parents or partners of adults diagnosed with NEAD. In comparison, I took the decision to remove the findings derived from the one 'friend' interview that I completed as I was mindful that the analysis identified some key differences to the parents and partners, possibly due to his different relationship to his caregiver role and felt it would be hard to compare his interview with others for the purpose of this thesis. I also took the decision to remove the findings derived from the joint 'parent-couple' interview that I completed, when two parents arrived for the interview and explained that despite our original agreement to interview just one of them, they wished to be interviewed together due to the fact that each other's support had been central to their experiences over recent years. However, in line with evidence that highlights that joint interviews are not simply "halfway between sole interviews and focus groups" but "generate interactions that are qualitatively different from either" (Seale, Charteris-Black, Dumelow, Locock, & Ziebland, 2008, p.108), I felt it was not possible to compare their findings with

interviews with individual family members and thus chose to remove them. I will return to briefly discuss these interviews in the discussion, in relation to possible ideas that they point to for future research.

5.6.4.2 *Decisions regarding the writing of research texts*

After reading each text for its content and performative features, I began by transforming the findings into a summary of each individual's narrative that aimed to focus on the key thematic storylines that interweaved and interconnected. In thinking about how to write the narrative introductions, I considered the importance that postmodern approaches to narrative emphasise on creating a text which invites the reader into a vicarious experience that leaves readers with a 'flavor' of the lives being depicted (Le Compte, 1993, as cited in Blumenreich, 2009). Similarly Tracy (2010) discussed the concept of 'resonance' in relation to the validity of qualitative research and wrote that narratives should be presented in such a way so as to "promote empathy, identification, and reverberation of the research" (p.844) by readers, in particular readers who may or may not have an experience of NEAD. In aiming to 'evoke', I therefore considered a number of factors in the production of my narratives.

- Firstly, I was initially drawn to the idea of writing participants' stories in the first-person narrative due to the sense of intimacy that this may offer to readers. However, I was influenced by Saukko's (2000) concerns about whether this would be confusing shifting from the participant's position back to my own position and thus was influenced by her preference of writing narratives using third-person prose, which also makes explicit to the reader that the stories are written from the outside.

- Secondly, I aimed to share the individuals' voice as much as possible and use their actual words. However, whilst it is conventional to show readers direct quotations (Tracy, 2010), which can often allow readers to read a different interpretation to the researchers, I recognised that this approach can often be deceptive and strips the words from the context in which they were told (Riessman, 2008). In comparison, I chose a narrative style, in which I absorbed

and interspersed the participants' words[9] within the prose of other elements of the interpretation and my narrative. In line with Saukko (2000), I hoped that this would highlight how my voice and the participants' are always entangled with each other, due to the co-constructed nature of conversations.

In writing the research texts, I was also constantly mindful of my privileged role as a researcher and reflected on a number of ethical questions, in particular those concerning the relational responsibilities that I held with my participants. For example, whilst I had agreed to use pseudonyms in replace of participant's names to preserve anonymity, I was required to make difficult decisions about which information to exclude to protect their identities and those of other individuals to whom they referred. Yet in addition to my ethical obligation to respect the relationship with my participants, I was also mindful of my "scholarly obligation to be in conversation with our peers" (Josselson, 2011, p.46) and thus my need to compose a research text that would also contribute to a scholarly discussion on the topic.

Finally, in considering the writing of the collective summary of the different thematic storylines and story 'types', I examined the transcripts to consider which stories to present. Whilst recognising that many stories were left untold due to the word limitations of the thesis, I was mindful that narratives are always partial and incomplete but endeavored to ensure that I used stories from each participant across all the storylines. Furthermore, drawing from Saukko's (2000) writing, I aimed not to muffle the individual voices but to bring them together into an "ensemble in which each of them begins to sound differently than it would have sounded on its own" (p.304). In the presentation of the results, I have therefore stitched them together around the key thematic storylines that recurred in the interviews and set each carer's story side by side with other carer's stories (Saukko, 2000). Finally, as some researchers argue that narratives are "linked inevitably to the questions that prompted

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[9] In presenting participants' words, some minor changes have been made. For example, any missing material is indicated with ellipses (…); where material has been added to their words for clarification, this is enclosed within [square brackets] and where participants showed expressions of emotion, these are also indicated in square brackets i.e. [pause]. All identifying information has been removed and pseudonyms have been used to ensure anonymity of participants.

them" (Wells, 2011, p.26), I have aimed to intersperse the types of questions that I asked, wherever possible, into the research texts.

5.6.4.3 *Seeking member reflections*

Tracy (2010) indicated that one path towards credibility of the research includes seeking input during the process of analysing data and producing the research texts. As such, after all the field texts had been analysed, a copy of the findings across the narratives was emailed out to each participant inviting feedback and comments.

Based on my social constructionist framework, this process did not aim towards accuracy of a single truth, as would be suggested through a process of 'member checking', but rather aimed to provide space for participants to share any reflections about the research findings; a process defined by Tracy (2010) as seeking 'member reflections'.

6   Findings

This chapter will present the findings of the co-constructed narratives told by eight family caregivers on the meanings of supporting an adult diagnosed with NEAD. The section is split into four parts. I will begin by introducing each of the participants[10]to situate each narrative in context. An overview of the findings will follow and then the two broad story 'types' that I identified when looking across the carers' narratives, in addition to their underlying dynamic, parallel and overlapping thematic storylines will be presented. This section also includes an integrated discussion about the relevance of these findings to other literature.

6.1   Participants

The interviews from four male caregivers (3 partners and 1 father) and four female caregivers (1 partner and 3 mothers) are presented below. Most described themselves as White British in origin, whilst one described herself as White European in origin. All cared for female adults who had been diagnosed with NEAD.

6.1.1   Robert

Robert was in his early thirties. His long-term partner, Jo (who was in her late twenties and lived with Robert) started seizures 4 ½ years ago and was diagnosed with NEAD 6 months after their onset. We met in his house.

6.1.2   Sarah

Sarah was in her late thirties. Her long-term partner, Susan (who was in her late thirties and lived with Sarah) had experienced her first seizure 7 months ago and was diagnosed with NEAD 5 months ago. We met in an interview room in a local council building.

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[10] these are presented in the order that I met them for interview

6.1.3   Sue

Sue was in her mid-late fifties. Her daughter, Lisa (who was in her early thirties and lived close to Sue) had experienced her first seizure 10 years ago and was diagnosed with NEAD 6 months ago. We met in a private room within a council library.

6.1.4   Amanda

Amanda was in her early fifties. Her daughter, Mary (who was in her late twenties and lived close to Amanda) had experienced her first seizure 6 ½ years ago and was diagnosed with NEAD 6 months later. We met in a university interview room.

6.1.5   Nicola

Nicola was in her late forties. Her daughter, Anna (who was in her early twenties and lived at home) had experienced her first seizure five years ago and was diagnosed with NEAD six months ago. We met in an interview room in a local council building.

6.1.6   Henry

Henry was in his late fifties. His daughter, Helen (who was in her late twenties and lived close to Henry) had experienced her first seizure 14 years ago and was diagnosed with NEAD 2 years ago. We met in a local council office.

6.1.7   Brian

Brian was in his early fifties. His wife, Julie (who was in her late forties and lived with Brian) started seizures 5 years ago and was diagnosed with NEAD 3 years ago. We met in a local council office.

6.1.8   James

James was in his early fifties. His long-term partner, Clare (who was in her late thirties and lived with James) had experienced her first seizure 16 months ago and was diagnosed with NEAD three months ago. We met in a room in the local council library.

6.2 Overview of findings

Pertinent to all the carers' narratives were stories which depicted the onset of their partner or daughter's seizures as being a frightening and disruptive event in their lives and an event which led to changes in many areas of their lives. Through their narratives, they illustrated how they attempted to make sense of and understand their changed experiences. In telling these stories on the day of the interview, their narratives fell into two different story 'types'. In stories of 'biographical continuity', carers told stories of understanding their caring role as an accepted and continuous part of their ongoing 'identity' as a partner and illustrated through their stories a sense of moving away from the initial period of 'disruption'. In comparison, in stories of 'biographical disruption', carers depicted that their experiences were having a significant impact on their daily lives and had resulted in significant biographical change. They illustrated through their stories a sense of struggling to move away from the initial period of 'disruption'.

In line with my epistemological assumptions, I have presented these narratives from the premise that they do not provide a direct insight into the lived experiences of the participants (Schult, 1967, as cited in Tracy, 2010) but represent the co-constructed and context dependent stories that were told in the interview. Furthermore, the story 'types' that are presented are not intended to represent rigid or static forms of understanding but are dynamic conceptual aids that represent the story or multiple and fluctuating stories that carers selected to tell in the interview and the stories that I heard most strongly. As with Frank's (1995) story 'types', they are not intended to create "a general unifying view" but are intended as "listening devices" (p.76) to hear the stories. Finally, in accordance with Clandinin and Connelly (2000), I recognise that "interpretations of events can always be otherwise" (p.31), are temporally and contextually dependent and are shaped by the narratives that I have brought to this research. I therefore acknowledge that readers are likely to derive their own, and possibly different meanings from the texts and as Saukko (2000) eloquently wrote, I invite "the reader not to take my words as universal truth but to argue with my partial perspective" (p.304).

6.3 Stories of 'biographical continuity': disruption to reconstruction

In this study, the narratives that fell under this story 'type' were told by the four partner caregivers and their narratives will be presented below.

Similar to previous literature which suggests that caregiving may be coped with through a strategy of 'biographical continuity' (Chamberlayne & King, 1997), these carers illustrated that they attempted to make sense of the disruptions that occurred following the onset of their partner's seizures and maintain a sense of normality or continuity by 'reconstructing' and integrating their new caregiving role into their lives. This process often seemed to be facilitated by their unquestioning assumption of caregiving being a natural or an expected outcome of their roles as partners. However, despite this strategy, their stories suggested that this did not prevent them from continuing to experience some aspects of their caring role as being disruptive in their lives.

6.3.1 The development of understandings about NEAD

A key characteristic of their narratives was the gradual development of understanding of NEAD over time, following the initial disruption of their partner's seizures.

6.3.1.1 _'Disruption' at onset_

In line with Bury's (1982) conceptualisation of chronic illness as a 'biographical disruption' whereby "structures of everyday life and the forms of knowledge which underpin them are disturbed" (p.169), all four carers portrayed a sense of disruption resulting from the onset of their partner's seizures and described this as being a period of shock, fear, confusion and/or frustration. This echoes previous research which has found that intimate partners of individuals with a range of chronic illnesses experience adverse reactions to the onset of illness (Bogosian, Moss-Morris, Yardley, & Dennison, 2009; Kowal, Johnson, & Lee, 2003; Maughan, Heyman, & Matthews, 2002).

Sarah, for example, responded to the opening question[11] by describing the onset of her partner's seizures as being "a scary thing to happen". She recalled that "it was so stressful" when Susan had her first seizure because "I didn't know what was going on" and spoke of being "in complete shock afterwards". Similarly, within the context of talking about the relief he felt when his partner was finally diagnosed with NEAD, Robert contrasted this to feelings of fear and uncertainty that he had felt "up until that point" when "I didn't know what's going on". In particular, he attributed his fear to the uncertainty as to whether his partner's seizures were going to kill her: "if you're having something and no one else has heard of it, it's like err have I got something that's going to kill me…it's really scary". Interestingly, Robert only spoke about these more negative emotions towards the latter stages of the interview, perhaps when he felt more at ease to do so (DeFina, 2009) and felt more able to share alternative stories to the dominant story of himself as a 'coper' that prevailed throughout his interview. In comparison, perhaps due to his awareness of the prevalence of misdiagnosis in this population (De Timary et al., 2002), he responded to an early question about his experiences at this time by describing that the onset was "easy for us…[because unlike some people with NEAD]…we were never told that it could be epilepsy or something else".

In comparison, a sense of fear was prevalent throughout James' story about this period of time. In response to a question about this time, he described the onset of his partner's seizures as being "extremely frightening" due to his fear that they represented something life-threatening. He manifested the unpredictability of Clare's seizures by pausing and using expressive sounds, e.g. "she would just literally [pause]…just go [click of fingers] onto the floor with no warning". He also spoke of the sense of confusion when they were passed between different doctors who gave them different diagnoses: "we went to the GP, er, initially who said it might be migraine...then we got referred to the specialist who immediately then checked for epilepsy, um through various tests and decided that...it wasn't epilepsy. Sent her to a cardiologist who said why are you wasting my time...it's epilepsy, and we said but no,

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[11] *'Can you begin by telling me in your own words something about your experiences of supporting (name of individual) with NEAD, beginning at a place where you feel is most appropriate to start'*

you know, the other doctor said no, it's not epilepsy...and so on. So we were confused". Whilst recalling that he "didn't understand [the seizures]", he emphasised that he tried to manage this by focusing his attention on Clare's needs: "my priority was just to be there...and make sure that, that I could sort of minimise any, any damage or distress with Clare". Yet, in the context of so many uncertainties, he highlighted that applying this strategy was not an easy task for him: "obviously that's, that's not easy when you don't know what's going on".

Finally, Brian's story about this period focused on the "frustrations" about the fact that his partner was "misdiagnosed" with "regular epilepsy" for two years, despite him "mentioning [and] complaining" to the Consultant that it wasn't epilepsy. He spontaneously told this story in response to the opening question and repeated it throughout his narrative, pointing to the likely significance of this event for him, perhaps due to it challenging some of his pre-conceived ideas about the competence of medical personnel and of scientific medicine. Linked to possible expectations of the competence of medical personnel and his perceptions of himself as "not obviously medically qualified", he conveyed a sense of struggling to challenge the Consultant's diagnosis in a more explicit and direct way:

> "obviously very frustrating, because despite the fact...you know I mentioned what I'd been observing and although I'm not obviously medically qualified...I know er the difference between...an epileptic seizure and despite me having, you know having my bit to say and mentioning it to the, to the Consultants...it went on for, well like I say two years before something changed...she stuck to her guns basically...but yeah, I'm not qualified, I'm not qualified, so er obviously I was wrong and she was right, but as it turned out it was the other way round".

With research suggesting that assertiveness in the medical encounter is more strongly associated with younger cohorts (Ryan, Anas, & Friedman, 2006), Brian's feelings may be a reflection of his generational beliefs about his role in the medical encounter.

Perhaps as a consequence of these potentially invalidating experiences from medical professionals, I wondered to what extent his storytelling was affected by me being in the role of a health professional and to what extent he felt able to talk about his experiences (in particular negative experiences) and believed that I would listen to and value his story. This was illustrated by the fact that within the first few minutes of the interview, he ended his first story by asking: "so anything else you'd like to know [laughs]", as if he positioned me in a more 'expert' position and as someone who needed to guide the telling of his story to ensure he shared 'appropriate information' with me. This was a pattern that appeared to continue throughout the interview, where Brian narrated brief stories, whilst I tentatively asked him to elaborate on them.

6.3.1.2 *'Reconstruction' of meanings*

In confronting the uncertainties and disruptions following the onset of their partner's seizures, these carers portrayed themselves as being engaged in a process, perhaps akin to 'narrative reconstruction' (G. Williams, 1984), in an attempt to make sense of the arrival of their partner's seizures and create some order to events and a sense of continuity. They typically presented themselves as developing some understandings over time.

For Sarah, she described that this process began prior to her partner's diagnosis of NEAD as she said: "we kinda knew…that it was dissociative before the diagnosis". Through her use of medical language when describing the tests that her partner received during the diagnostic process (e.g. "we then did the battery of tests with regards to EEGs, ECGs, MRIs and then finally the video-telemetry"), she portrayed herself as someone with a good academic understanding of medical issues and in response to the opening question, spoke in a confident tone about the condition making sense to her: "the reason we believe [Susan] has it is because of work stress and bullying". Miczo (2003) wrote that narrators can acquire social status by virtue of their possession of special knowledge. This 'special knowledge' portrayed by Sarah appeared to minimise the power differentials between us and provided an equal platform from which to conduct the interview with assumptions on both sides that there was a shared understanding in relation to NEAD.

In comparison, for Robert, this process of meaning 'reconstruction' followed the diagnosis of his partner's seizures. He recalled this as being a time of relief due to the fact "that it [Joanne's seizures] had a name" and to learn that you "can't die as a direct result of a NEAD seizure"; mirroring reactions that have been reported by some individuals with NEAD (Carton et al., 2003; Thompson et al., 2009) and chronic fatigue syndrome (Ax, Gregg, & Jones, 1997). Whilst he initially said that he found it "a bit weird" that "there's something that can cause seizures other than epilepsy", he explained that similar to Sarah, he gained a lot of understanding about NEAD by reading about it and spoke of this being a very "interesting" process, highlighting a perception that some aspects of his experiences were positive for him. He spoke confidently about his understanding of NEAD and appeared to locate his understanding firmly within a psychological explanation: "It's your body responding to an emotional stress that's doing this…it is a mental illness". Furthermore, by creating some order in the events in his partner's life, he spoke of the diagnosis making "a lot of sense" and recounted claims to have developed a personal understanding that had allowed him to "come to terms with it" and perhaps to 'come to terms with' his understandings that "the condition's not, we've been told the condition is not going to go away".

Brian also recounted that the diagnosis was associated with feelings of relief and he described that for him and his partner, this meant getting "on the right track…at last". In response to a question about his understanding, Brian illustrated that he had developed some understandings over time, for example, he spoke of thinking that his partner's "depression has something to do with it". However, at the same time, by repetitively referring to epilepsy as "regular epilepsy" in his narrative, this portrayed a possible lack of understanding about NEAD and a perception that in comparison to "regular epilepsy", he perceived NEAD as "irregular" or even something else entirely different. Furthermore, he also appeared to narrate a relatively passive position in relation to his understandings, thus contrasting with Robert and Sarah, by locating the power and understanding with others "I don't really know err too much about it…I try not to understand it; I just let the, the, the experts get on with it". It is possible that similar to some of the findings in Kuyper and Wester's (1998) study on partner

caregivers, this pointed to an implicit fear of Brian's that understanding may involve more responsibility in terms of the management of the condition. It was interesting to notice that after revealing some aspect of uncertainty or struggle in his story, he often returned to a repetitive phrase such as "but at least things are moving in the right [following the diagnosis]…I believe things are moving in the right direction now", suggesting that this journey back to 'normality' was enabling him to perceive a sense of continuity in his future.

Finally, in response to a question about his reactions following the diagnosis of his partner's seizures, James identified this period of time as being a turning point in their experiences and explained that "just having a diagnosis and, and being justified in, in saying, you know, there is something wrong here…was a relief for both of us" and enabled him, as he described to 'change his thinking': "we've got a diagnosis so what are we gonna do about it". Furthermore, when asked about his change in understanding over time, James spoke about "definitely" getting a better understanding over time, which he attributed to the clear explanation about NEAD that they received from Clare's Consultant. However, at the same time, he repetitively asked rhetorical questions such as, "where does that come from? What's causing that?" when referring to Clare's seizures and the use of his questioning suggested that, at the time of the interview (perhaps due to the relatively recent diagnosis of his partner's seizures), he was still engaged in a struggle to fully make sense of her experiences. His selection of stories, for example, referring to the "absolute gobbledygook" that Clare verbalises during her seizures, in addition to the telling about her "fixation of mangoes", which he followed with an aside to the audience that mangoes "do not play a part in her life", appeared to further emphasise his current sense of confusion and fear in relation to the seemingly random and bizarre images during episodes. In talking about the future, James spoke of his hope that psychological therapy may "ease it" but similar to Brian, alluded to his uncertainty about whether it will ultimately "help with the NEAD, I don't know".

6.3.1.3 Summary of the development understandings about NEAD storyline

Similar to Whitehead (2006) who found that receiving the diagnosis of chronic fatigue syndrome brought with it positive changes in 'identity' for those with the condition, the narratives told by the partners in this study suggested that the diagnosis was experienced as a relatively positive event or a turning point, which perhaps served to legitimise the caring role for some (Jutel, 2010) and act as an anchor or springboard for a more focused exploration of the condition. By creating some 'links with the past' (Becker, 1997), this may have helped them to find a relatively "meaningful place for the illness in their lives" (Lawton, 2003, p.27) and a sense of continuity that enabled them to move forward, in spite of some continuing uncertainties. Similar to Frank's (1995) 'quest' narratives, their stories suggested that they had attempted to "accept [the] illness" and viewed it as a "challenge and an impetus for change" (p.166).

6.3.2 Living with NEAD and managing lifestyle changes

Perhaps facilitated by their developing understandings, these partners told parallel stories about their relatively 'positive' responses to the many changes that had occurred in their lives following the onset of their partner's seizures. Similar to the changes reported by partners of other individuals with chronic illness, they spoke about changes in their relationships with their partner (Bogosian et al., 2009; Fernandez et al., 2006; Paulson et al., 2003), and their working, financial and social lives (Bogosian et al., 2009; Kemler & Furnee, 2002). Through their narratives, they portrayed a sense that despite the challenges that accompanied the changes in their lives, they viewed the changes as being part of their role as a partner. This mirrors the findings of Ax, Gregg and Jones (2002) who identified that spouse caregivers of individuals with chronic fatigue syndrome (CFS) appeared to 'adjust' to the illness and 'unconditionally accept' it, due to their commitment, as expressed in their marriage vows, to the 'sufferer'.

6.3.2.1 Changing relationships with partner

One change that was particular apparent in Sarah's interview was her changing relationship with her partner. She began her interview by describing their life before her partner's seizures, when they spent extended periods of time away from each other

due to work: "before all this started, we were both sort of working in the corporate world, um, kind of very fast pace of life with regards to travelling and being away from home and working long hours". She subsequently contrasted this to the "big paradigm shifts" that took place in their relationship when she started to work at home to look after Susan, thus resulting in them "being together 24-7". However, she immediately framed these 'big' shifts within the greater story of their "strong relationship" and described how they "weren't really a problem, it was just that we had to kind of adjust...and make sure that you get time apart from each other".

Within the context of this story, she orientated her audience to their general coping strategy of "just getting on" with the changes in their lives, in an attempt to "try and make and maintain that normality". Perhaps in line with the 'business identity' that she introduced in the opening lines of her narrative, she appeared to present herself as a strong and capable individual who had adapted successfully to their new situation, thus appearing to portray a continuity in this aspect of her 'identity'. Similar to some of the carers in Adamson and Donovan's (2005) study, she did not appear to identify with a change in 'identity' and in particular stated that "we don't really identify with the kind of carer sufferer[12] role....it's just your looking after your partner". Whilst the concept of the 'informal carer' is now a social 'identity' written into policy and law (Henderson, 2001), Sarah's story corresponded to similar findings reported by Henderson (2001) and in the recent DOH Carers Strategy (DOH, 2010), that highlight that not all people subscribe to the 'identity' of 'carer' or 'cared for' in their relationship. These findings suggest that an alternative framework may be needed for people who do not see themselves as 'carer' but who are given this 'identity' by policy makers and professionals.

Despite the 'coping' persona that Sarah portrayed over the course of her interview, her narrative revealed that certain aspects of her experiences were more disruptive. In particular, when talking about her changing relationship with her partner, she described that "the [pause] the living with someone that has seizures is the, I think

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[12] It is likely that the reference to the word 'sufferer' in Sarah's story relates to the terminology that is used by the NEAD Trust support group, who originally defined themselves as being a charity for 'sufferers' with NEAD, their families and carers.

that's the scariest bit", with her use of the present tense suggesting the ongoing nature of this fear. She gave an example from her past when a seizure left her "freaking out" because "it looked like a murder scene" and spoke emotionally about feeling "quite lonely" during her partner's seizures, positioning this in contrast to their relationship at other times, i.e. "Susan is like my rock in everything else in life". She also described that as a consequence of her worries, she sometimes "get[s] overprotective of her late at night…kind of keeping an ear on her" to ensure her partner doesn't hurt herself during a seizure. However, as if to re-position herself to the 'coping' persona that dominated her narrative, she ended this story by normalising this as being "just the nature of, you know, living with someone with this" and spoke of the steps she had taken to "stop doing" the "over-protectiveness" and give her partner more space.

James also placed particular emphasis on his changing connection with his partner by locating a story about this in the opening lines of his interview. In response to the opening question, he began his interview by saying: "Right. I think key word for me is frustration" and closely followed this with: "it actually takes away a lot of our time together". He subsequently recounted that he was often physically "alone" in the evenings due to his partner needing a lot of sleep and implied through his stories that they were often engaged in disjointed and repetitive conversations following her seizures. Similar to Sarah, he also spoke of the "24-7" nature of their relationship and due to his fear that his partner may harm herself if he left her alone in the home, he spoke of the difficulty of leaving her and thus do the things that he had previously enjoyed. By turning his attention to the interview context, he referred to the degree of planning that had to take place to ensure he could be apart from Clare to meet with me: "I mean today I'm here with you. Now Clare is across the road in the bingo hall…it has to take that sort of arrangement" and perhaps felt that this would enable me to develop more of an understanding of his difficulties.

Whilst James' stories, such as the one above, illustrated the significant disruption of the "life changing" impact of NEAD on his life, he appeared to use his narrative to frame these changes within the context of a strong personal and continuous narrative about himself as a 'carer' or a '*good* carer', with the latter perhaps influenced by the

dominant moral discourses surrounding informal caregiving in the UK (Pickard, 2010). Similar to the spouse caregivers in Axe, Gregg and Jones' (2002) study, he appeared to present himself as 'accepting' the illness as part of his life and in comparison to Sarah, illustrated that the identity of a 'carer' was something he appeared to aspire to (Henderson, 2001). In line with this, he cast himself as a loving carer towards Clare: "I'm very proud of looking after her and being her carer" and as someone who was willing or "prepared to do anything for her for whatever length of time is required". He also described that his nature "is to work with people who, who have different types of illness" and spoke of drawing on his desire to "maximise life's opportunities" and "make the best quality of life" for those he cares for, including his partner. Furthermore, within the context of talking about their struggles, he often compared his experiences with other carers, perhaps in an attempt to normalise them and illustrated a sense of shared 'identity' with other 'carers': "you know...all carers go through that, at some point". This may have been facilitated by his previous roles as a 'carer'.

Yet, in spite of the '*good* carer' image that he portrayed throughout this story, other aspects of his narrative briefly pointed to the fact that "it's not easy...it is a struggle and sometimes...I'm really depressed", showing that beneath the surface, aspects of his caring role were more of a struggle for him. For example, when speaking about his loss of activities due to the "24-7" nature of their relationship, he explained that "it's a bit of a hard balance to make", perhaps on account of it denying some of his own 'identity'. In fact, when talking about the future, he spoke of needing to prioritise some of his own needs and "pursue, um, the things that, that I want to do", such as voluntary work. Whilst James' stories echo previous research that has illustrated that partner caregivers may experience struggles in negotiating time to engage in their own meaningful activities (Kuyper & Wester, 1998; Rolland, 1994) or as Corbin and Strauss (1988) described, may experience a "tug-of-war phenomenon" when managing these conflicts, I wondered whether James felt guilty at times in sharing some of his more negative feelings with me. As if to justify these feelings, he appeared to want to remind me of his commitment towards his partner at the start of sentences: "as much as I love her and everything, I would just like to just go

somewhere for the day and do something completely different on my own just, just to, you know, freshen up and go back and start again".

In addition to speaking about changes in their relationships with their partner, these carers also spoke about changes that took place in their working lives.

Brian, for example, explained that he stopped work to look after his partner. In response to a question to prompt him to expand on the effect on this change for him, he spoke of facing such changes "like a duck to water" and explained that "looking after my wife…is my priority…her well-being is obviously more important than a silly little office job". Through these stories, he portrayed a sense that his caring role was integral to his commitment to their relationship and highlighted this further when he explained that "if the roles were reversed, she would look after me".

For Robert, he explained that his decision to give up work was made in the context of his partner being pregnant and his fears of her harming herself and the baby if she had a seizure on the stairs. He recounted a graphic story about the time when he returned home from work to find his partner "on a stone floor with broken glass all around her". In evaluating this event, he explained that "I couldn't take it anymore… that was the last day I worked" and said that he "wasn't too bothered about [stopping] the job", perhaps due to it fitting the ethos that he had always brought to his work: "I work to live not live to work".

Similar to Brian, it also appeared that Robert made sense of changes such as his role change from employee to caregiver within the context of his relationship with his partner: "the person that I love needed help so I just helped…it's that simple really". He also opened his narrative by casting himself as someone who coped from the outset: "you just kind of get on with it", perhaps reflecting recent research into male caregiving that suggests that male caregivers approach care work in ways that create and sustain feelings of masculinity, by using strategies such as distancing from

emotions or minimizing the care work's disruptions on their lives (Calsanti & King, 2007; Russell, 2001).

Lindemann (2010) wrote that "humans are *storylivers* rather than just storytellers" (p.31) and may use stories to construct a particular narrative of themselves. Thus, in telling their stories about 'just getting on with it', it was possible that this enabled Robert and Brian to construct themselves as 'successful' carers, in addition to enabling them to communicate a more positive message to their audience. However, in line with previous caregiver research, it was also possible that their story-telling was influenced by ideas of 'positive thinking' being a moral obligation; as "something you have to do" (Wilkinson & Kitzinger, 2000, p. 806) and by a sense that they did not have 'permission' to complain about or discuss the negative aspects of their experiences with me in the interview (Adamson & Donovan, 2005).

Interestingly, Robert followed his story about it being that "simple really" with a brief and contradictory story: "um, you don't realise how hard it is until you stop…it's mentally tiring", thus briefly revealing a more vulnerable view of himself. He went on to describe the use of his "carer's hat", which he said enabled him to deal with things in a "more analytical…as opposed to an emotional way" and whilst he made reference again to the emotional impact of his role when he described that he "occasionally cries" in his sleep, he immediately followed this with but "no-one knows" and positioned himself within a gendered narrative: "I'm a guy and clearly we don't cry [laughs]", with the laugh perhaps an illustration of the irony of this statement.

6.3.3 Encountering others and working towards managing their sense making of NEAD

A final storyline that was apparent in the narratives of most of these partners related to their encounters over time with others and in particular, their encounters with the misunderstandings and critical judgments of others. Whilst they typically portrayed themselves as attempting to manage these responses, perhaps facilitated by their perception of the caregiving role being a 'normal' part of their role as a partner, their

stories also illustrated that this was one aspect that they perhaps struggled with to a greater extent.

6.3.3.1 *Encountering misunderstandings*

Similar to the findings reported by other partners of individuals with medically unexplained conditions (Paulson et al., 2006), these partners reported a perception that other people did not understand NEAD. For example, James said: "you tell them, nobody says, oh yeah, you know my uncle had that". When I asked how James responded to the misunderstandings of others, he said that the "easiest way to explain it" is to say "basically [sigh] that it's like epilepsy but it's not". Through his sigh and use of phrases such as "so you say, well...", I wondered whether these conversations felt repetitive and wearisome for James and thus asked what it was like for him needing to offer such an explanation. In contrast to the performative indicators of his story-telling, he portrayed a sense that it was perhaps helpful for him to normalise this (possibly inevitable) experience and spoke of the explanation now coming "second nature" to him due to the frequency of which he had to use it.

Similarly, Brian explained that "the general public probably don't know about it....it's almost, well it's not a secret like, but it's not very common". In response to a similar question from me about his responses to this, he once again responded by reminding me "er, um...well first of all my priority is, is, is looking after Julie, looking after my wife. Um...that's that's not a problem....that's frustrating but at least in my wife's case things are starting to move now", thus portraying a sense that in line with previous stories that he told, he may attempt to distance himself away from the emotional feelings to manage this situation. When he later recounted how he explained his partner's seizures to others: "I say, 'well it's not really epilepsy but it's similar and it's nothing to worry about' and usually...she'll wake up with no fuss", this story also suggested that he may attempt to minimise the condition when speaking to others, perhaps to avoid difficult or confusing conversations about NEAD.

Finally, in comparison to the 'ignorance' of the general public, Robert explained in an angry tone that the people that really "get" him "are the medical professionals....they

should know...about this condition". Over the course of his narrative, he portrayed himself as taking a relatively assertive position vis-a-vis the perceived medical "ignorance". For example, he recalled an encounter with one "ignorant" GP whom he perceived was "saying it's faking", who didn't want to know about the condition and "refused to listen" to his explanation of NEAD. As such, he explained that "I had to leave the room, it's like I'm not dealing with you...you're not interested, therefore I'm not going to speak to you, we'll just go to another doctor, you're clearly no good". Similar to the husbands of individuals with fibromyalgia in Soderberg et al's. (2003) study, Robert presented himself as taking an advocacy role for his partner in an attempt to get NEAD accepted by members of the medical professional.

6.3.3.2 *Encountering critical judgements*

Carers also spoke about encountering the critical judgements of others, in particular following their partner's seizures in public. Robert, for example, explained that many of his and his partner's friends had "abandoned" them, something which he attributed to likely feelings of embarrassment, perhaps reflective of a societal stigma about people who are unable to control their bodies (Goffman, 1963, as cited in Kleinman, 1988): "it's just embarrassed, embarrassed that someone that's with them is having a seizure, don't know how to deal with it, therefore, instead of learning how to deal with it...just [pause] don't...it seems to be quite a typical response from what I've learned". Whilst suggesting that they were able to continue going out, in spite of these reactions from others, he indirectly referred to his feelings of embarrassment, "[not] by Joanne having a seizure...but...for her because I knew she was embarrassed by it". As suggested by Chamberlayne and King (1997), this story may reflect how "'appearing publicly' with a suddenly disabled partner can be painful for the carer as well as the disabled spouse" (p.602) and may have implications on their biographical adjustment to caregiving.

Similarly, through his use of language when recounting a time when his partner, Clare had a seizure in public, James spoke of his perception that others appear to mock her: "everybody's oh that woman's passed out, ner, ner, ner" and hold derogatory perceptions towards her: "does this woman belong to anybody". Furthermore, through

this story, he also spoke of his perception that he, as Clare's carer is often judged by others as a result of his approach to Clare's seizures:

> "and then when you sort of get her up and say come one Clare, come and sit down, people think you're actually being cruel, that you…should be doing more. Do you need a doctor? No, it's fine…people are like oh, he's, he's not being very kind to her, he's just sat her up and said you'll be alright in a minute, but that's because we know but they don't. It's quite difficult sometimes."

Perhaps as a way to minimise these experiences, he explained that "my priority is to make sure Clare's alright and what other people think is, you know... by the way [laughs]. Basically". However, his laughter and story suggest otherwise and imply that the reactions of others can at times impact on or threaten aspects of his caring 'identity'.

A sense that NEAD was doubted by other people was also highlighted in their narratives. For example, whilst Robert acknowledged that he was never told directly by doctors that his partner was "faking it", he spoke of gaining this impression during his encounters with some professionals: "a couple of them had heard and just assumed she was faking it, so they didn't say directly to me but, um, that's the impression I was given". In a stark change in tone, he posed a rhetorical question: "it makes me really angry to think that someone's going to fake something like this, I mean there's no point...why would we fake for benefits?" and followed this immediately by describing their previous well-paid job roles, as if to legitimise their position and take an active stance in relation to possible perceptions that they had not previously contributed to society. James also spoke of being exposed to similar attitudes from family members who think "we're just trying it on", with his use of the word 'we' illustrating his perception that the discourses around NEAD being a 'fake' condition also impacted on his sense of 'identity'. Thus, these stories point to the influential role that social understandings could play on how the "new reality [as caregiver] is socially constructed by the caregiver" (Kyriacou, 2010, p.172).

6.3.3.3 Encountering support from others

6.3.3.3.1 From family, friends and the general public

Whilst previous research has highlighted that partners of individuals with medically unexplained conditions frequently report feelings of isolation (Paulson et al., 2006), stories about the lack of support or isolation from friends or family were relatively absent in these carers' narratives or were anchored in the past. For example, Robert said that "we felt alone" following the diagnosis, due to their encounters with the misunderstandings of others and their lack of awareness about other people with the condition. In comparison, through their narratives, carers included characters that were perceived as playing important roles in offering them support and thus, their narratives appear to support the literature which points to the value of informal support over formal support for family caregivers (Smith, Fullmer & Torbin, 1994; as cited in Walden, Pistrang, & Joyce, 2000) and which suggests that individuals and spouses with good social support are able to better 'adapt' to chronic illness than those without (Revenson & Majerovitz, 1990).

Sarah, for example, spoke about the valuable role of friends and spontaneously made reference to work colleagues and friends who "understood" NEAD and were interested in learning more about it. In comparison to the other partner caregivers, she did not tell stories about the misunderstandings or critical judgements of others and it was possible that her positive experiences with family and friends enabled her to ignore or avoid such negative interactions with others. James also included some characters in his narrative and made reference to the gradual steps that he had taken to bring members of their local community "into our confidence". Whilst speaking of his recognition that "all carers need to have a break", he spoke of the process of seeking support from others as taking time. This appears to mirror the gradual process that male caregivers have reported to engage in when making the decision to access formal support (Coe & Neufeld, 1999).

Chamberlayne and King (1997) also wrote that where "servicing others is so entangled in a carer's life", it may be that "more radical adjustments to the new and

often worsening reality, such as calling in outside support, threatens the sense of 'self' and such carers may be actively, even aggressively, defying change" (p.606). It was possible that for James, seeking the support of others was perceived as a radical adjustment that may not have fitted with his self-definition as a 'carer' and thus may account for why it took him time to begin this process. By pre-empting his story about carers needing a break with "I know it sounds selfish but..." it was possible that he was attempting to protect himself from perceived critical judgements from others. In addition, it also illustrated that this struggle may have been ongoing at the time of the interview.

Finding support from others in similar circumstances was also very important for some carers. For example, whilst Brian described himself as someone who didn't "really need any support as such, I just get on with it", he narrated a highly detailed and spontaneous story about meeting someone whose wife had received a diagnosis of NEAD. His use of emotional language, for example, "I just couldn't believe it!" and "I says, 'You're kidding'!" in addition to the repetitive telling of this story throughout and after the interview suggested the significance of this event for him. Furthermore, most carers spoke about the support they received from the NEAD Trust support group in terms of the opportunities it provided for meeting other people in a similar situation. Robert, in particular, described that this helped them to "feel less alone" following his partner's diagnosis and Sarah spoke of the benefits of "learning more about the condition" by being in contact with group members.

6.3.3.3.2 From services

In comparison to stories about support from friends, some carers narrated stories about the lack of support from services in response to direct questions about this. Robert, for example, described that the support from services had been "completely zero" and James spoke about his frustrations about the lack of information that they received at the time of diagnosis and compared this to the type of information that is available for other conditions: "if you get a diagnosis for cancer, or you know, Alzhe...you get information...but it just felt well why is there nothing for this?" Similarly, Sarah explained that there had been little information online about NEAD.

However, most carers also recounted stories about establishing some positive and helpful relationships with professionals. Sarah, in particular spoke about her encounters with services as being "a really positive experience" and seemed to attribute a lot of this to being able to access the private medical provider, BUPA. When I asked her to expand on this, she emphasised that it was good to know that "you have someone in your corner and we have a continuity of care", with the change from the 'you' and 'we' almost implicitly contrasting private and NHS care, and described their neurologist as being "amazing". Furthermore, she also positioned herself as taking an active and dominant role in relation to seeking appropriate support. For example, she described herself as being "like a bulldog when it came to the medical profession" and taking "charge of the whole medical thing".

6.3.4 Summary of stories of 'biographical continuity'

In summary, at the time of the interview, these carers told stories which illustrated a sense of movement from disruption to reconstruction over time. Their stories depicted the diagnosis as being a relatively positive turning point following the initial disruption after their partner's first seizure, and portrayed a sense that they had found a way of integrating aspects of their caregiving role into their lives.

Drawing on literature which suggests that assigning meaning to an illness is an effective coping strategy (Coyne, 1997), it was possible that their developing understandings about NEAD had contributed to their abilities to integrate aspects of their caring experiences into their lives. Similarly, research with caregivers (Stern et al., 1999) and with individuals with NEAD (Dickinson et al., 2010) has pointed to the importance of sense making in shaping the experiences of individuals. Through their stories they also illustrated that similar to some of the carers in Adamson and Donovan's (2005) study, they appeared to draw on their ongoing 'identity' as a partner to understand their caring role as being an accepted part of their lives, perhaps influenced by their long-term commitment to their partners.

Whilst they typically depicted their stories in this way, each carer revealed more vulnerable stories of themselves and their experiences, although these were relatively

brief. As has been discussed throughout this section, a number of factors relating to the relational setting of the interview may have influenced how they chose to frame their experiences (Josselson, 2011) including the possibility that their stories were influenced by some of the dominant discourses and language surrounding informal and 'good' caregiving (Pickard, 2010), by ideas that they lacked the permission or felt guilty, as partners, to reveal more negative stories about their experiences (Adamson & Donovan, 2005) and as a result of wanting to illustrate to me, as a professional, their capabilities as a carer. Finally, with the majority of the partners being male caregivers, it was also possible that gender factors shaped their meaning making, as research points to the fact that male caregivers may experience fewer negative consequences than female caregivers (Coe & Neufeld, 1999; Kuyper & Wester, 1998). However, as with this study, this finding may also be related to the stories they chose to tell, with research suggesting that women are generally more comfortable than men in disclosing negative emotions (Hayes, Zimmerman, & Boylstein, 2010).

6.4 Stories of 'biographical disruption': a struggle to reconstruct

In comparison to the previous partners, the four parent caregivers told narratives which depicted caring as resulting in more significant and longer-lasting biographical changes or 'biographical disruption' (Bury, 1982) and their narratives will be presented below. Their stories pointed to the difficulties in disentangling the events that had arisen from their narrative as a parent.

6.4.1 Struggling to develop understandings about NEAD

A key characteristic of these narratives was a sense that caregivers struggled to develop many understandings over time about NEAD, following the initial onset of their daughter's seizures.

6.4.1.1 'Disruption' at onset

Similar to the previous carers, these carers' narratives depicted the disruptive impact of the onset of their daughters' seizures on their lives. However, in contrast, most of these carers narrated more detailed stories about this period of time (perhaps reflecting the lengthy process that they experienced between the onset of seizures and subsequent diagnosis of NEAD) and often spontaneously narrated these in response to the opening question of the interview.

Pertinent to their narratives was a sense of chaos and frustration. This was particularly evident in Henry's narrative who, at the outset of his interview, recalled how "painfully aware" he was that "for at least a decade, as far as we were concerned in the hospital, um Helen was, was just, you know and there wasn't a diagnosis". His unfinished sentences appeared to reflect the lack of terminology to describe Helen's 'seizures': "you've got this strange, you fall down every now and then". He told of wishing she had epilepsy, "then at least we could have a firm diagnosis" and spoke of his fear and his perception that "here she was compared to the other two [of his children], she wasn't normal".

Without a diagnosis, he spoke of his awareness that the attitude from medical professionals appeared to be: "just get on with it type of thing" and illustrated his

frustrations by recounting an experience when "I got close to…sort of picketing the hospital…or…going after the doctor with an axe and saying look do something". Adamson (1997) wrote that the "normative assumption within scientific medicine is that the problem [i.e. symptoms]…can in principle, be solved" (p.135) and that doctors can alleviate feelings of 'existential uncertainty' i.e. "an individual's…realisation that the future life of his or her mind, body and self is in jeopardy" (p.134). This story of Henry's highlighted the emotional challenges in living in what Corbin and Strauss (1985) called 'diagnostic limbo' and the challenges that caregivers may experience when medical encounters fall short of the anticipated ideal. Perhaps to justify this graphic story to his audience, Henry portrayed a sense of powerlessness by saying that "you can't do anything about [the lack of diagnosis]" and his use of present tense pointed to the vivid (Riessman, 2008) and possibly ongoing nature of this experience. Furthermore, research has examined how narrators position themselves through their talk (De Fina, Schiffrin & Bamberg, 2006, as cited in Wells, 2006) and by shifting from the use of the word *I* in previous sentences to the use of the word *you* in this sentence, it was possible that he wanted to reflect the likelihood that he was not alone in having this sort of encounter and perhaps appeal for the empathetic understanding of the audience (Tannen, 1989, as cited in Langellier, 2001) and redirect any potential attributions of blame about his feelings of aggression in this situation away from himself.

The range of words used in Nicola's narrative to describe her daughter's seizures may have also reflected her experience that "there was no label" and no "answer" for 4 ½ years following their onset. For example, she described that her daughter often "blacked out", had "drop attacks" and "collapsed". Sue, who opened her narrative by recalling the context and minutiae of the meal they were eating when Lisa had her first seizure: "It was a Friday night. We were having salad and crusty rolls", also recalled a sense of chaos in her narrative. In particular, her story illustrated that the understandings were constantly shifting over the 9 year period between the onset and final diagnosis and she recounted her frustrations in being unable to "make sense of it all" and believing that no understanding was ever "going to be the right answer".

In comparison, Amanda recounted a relatively brief story about the onset, which she told in response to a direct question from me. Whilst this may have reflected the briefer period of time that her daughter experienced between onset and diagnosis in comparison to the previous three, it may have also reflected the fact that there appeared to be one predominant understanding that it may have been epilepsy. And for Amanda, she described that this was scary for her: "I was thinking Oh God, no, I hope it's not epilepsy, where's it come from?", in particular due to her fear that such a diagnosis would "impede her" daughter in her life.

6.4.1.2 *Struggling to 'reconstruct' meanings*

Perhaps as a result of their more chaotic stories of onset, the narratives they told reflected a more vigorous process of searching for meaning compared to the partner caregivers; a process which has been well documented in other chronic illnesses within the context of uncertainty (Brown & Williams, 1995; Osborn & Smith, 1998). Moreover, their narratives illustrated that for these parent caregivers, the diagnosis appeared to offer them with little relief in their search for understanding.

Similar to some of the partner caregivers, Henry constructed the diagnosis as being a relatively positive experience in that having a label "somehow made it easier [to] bang on the table and say look it's a recognised medical condition, it's quite rare but it is a recognised medical condition". Thus, the diagnosis may have provided him with recourse to some form of categorical 'identity' (Jutel, 2010); something which has also been identified when individuals with MUS receive a diagnostic label (Nettleton, Watt, O'Malley & Duffey, 2005). However, whilst Henry spoke of feeling "more comfortable" over time with the diagnosis, he alluded to contradictory feelings in relation to the diagnosis, as he opened his interview by saying "it's [i.e. NEAD], it's a very disturbing condition", with the present tense perhaps suggesting that this was a current perception of his. Furthermore, he explained that he constantly "racked his brain" for possible causes and said that he still hadn't ruled out the possible link of his daughter's seizures with her migraines. In line with this, he also recounted a detailed story about "a slight niggle at the back of my mind" about what it meant to be a father to a daughter with NEAD. For example, he spoke of questioning whether medical

professionals "are looking at me…and thinking…well perhaps you've been a bad dad, perhaps you didn't bring her up very well". When asked if these concerns had changed over time, he responded by saying: "I think, if anything it's getting worse".

In comparison to Henry, whilst Amanda recalled feeling relieved that her daughter didn't have epilepsy when they received the NEAD diagnosis, she described that the diagnosis raised uncertainties for her; uncertainties which appeared to be ongoing at the time of the interview. For example, in response to a direct question about her understanding of NEAD, she said "I don't think I understand it anymore than I did when she was first diagnosed". In particular, she described herself as finding NEAD "hard to grasp…I was one of these people who like an answer to everything and there isn't answer to that" and finding the idea of psychological therapy hard to understand: "I find it harder to understand than taking a tablet for it really". She also spoke doubtfully of how it was possible to "distinguish between" epilepsy and NEAD and of an anticipated future where her daughter is "never gonna get rid of these NEAD bits…I don't know what the future for this sort of condition holds…to get this NEAD sort of psychologic…you know, out of your mind". Her use of language when describing NEAD, e.g. "this NEAD" or "these NEAD bits", appeared to further illustrate this sense of confusion and perhaps illustrated her attempts to objectify and externalize the condition, as a way of trying to understand it.

Furthermore, the diagnosis appeared to hold little significance in Sue and Nicola's narratives, perhaps as a result of a history of changing understandings where "pseudoseizures" had previously been mentioned but not followed up. For example, Sue recalled that after the first time of hearing "non-epileptic seizures" she remembered thinking "we haven't got an answer…we're starting all over again trying to get…trying to get um, a rhyme or reason for why she's like it". Similarly, after the second and "final" diagnosis, she said she was "not convinced. I'm sorry, I'm not"; with her ironic use of the word 'sorry' perhaps serving to reinforce her sense of doubt in relation to the diagnosis.

Similar to Amanda, Sue described herself as needing "a reason, you know" and in particular, to understand how her daughter, whom she described as being "such a happy go lucky kid", could be "dealt with this". Without "a reason" and perhaps due to her perception of psychological therapy being "a load of twaddle [laughs]" (with the laugh perhaps an indirect illustration of her recognition of whom she was telling this story to) she explained that "there doesn't seem to be any end of the…any light at the end of the tunnel" and spoke of the condition making her feel "guilty. It makes me feel as though it's my fault". Perhaps to convince both herself and the audience that she did nothing that she could be blamed for, she said: "but you've done the best you can…she didn't get treated any different". In an attempt to manage these feelings of guilt, there was a sense through the telling of her story that she attempted to distance herself from the condition by the use of the impersonal pronoun 'they' to refer to individuals with NEAD: "it's not in their heads…they don't want to be like that". At the same time, by drawing me into the story through the use of 'we': "it must be awful. We don't know what it's like, do we?" it was as though she needed reassurance from me, as an outsider, that the condition was a confusing one and difficult to understand.

For Nicola, the use of the word "pseudo.." that was used at the time of the "first" diagnosis "really did make you feel you were making it up, that it wasn't real, that it wasn't happening" and whilst she said that the 'NEAD' terminology made it feel "a little bit more real", she explained that "you don't…understand it anymore…it's…still disbelief". And for Nicola, the lack of understanding "is the biggest problem…you just think, how can you do it to yourself?" Through this question, it was possible that Nicola was communicating an implicit belief about the seizures being under her daughter's volitional control. She also shared that the "hardest thing" is getting "your head round that your body will do that to you" and dramatically enhanced this difficulty by recounting a story about a seizure that Anna had had on a "metal staircase". In telling the story, she began by describing the location as not being "a nice place to fall…it's not a soft carpet, it's not nothing, it's great big industrial width erm, metal staircase", before describing the seizure, with an onomatopoeia and an expressive sound: "and boom, [clicks fingers], went".

The choice of this particular story, in addition to asking a rhetorical question to draw me and other listeners in, such as "why would your body decide, oh yeah, I'm in a dangerous place…then choose that point?" served to accentuate her sense of sheer confusion, and possible feelings of dread and horror about the nature of NEAD. Similar to Amanda and Sue, she positioned herself as needing "an answer because it's not logical" and attributed this to the fact that "it's not a diagnosed problem, it's not something, like I said, it's not epilepsy, it's not diabetes, it's not cancer…it's in your head and that's the hardest thing". As a consequence of struggling to find an "answer" and the "magic wand" that she has been waiting for (something which she repeated five times throughout her narrative), she described a hopeless outlook for the future: "there's no end to it…it's six years now".

6.4.1.3 *Summary of struggling to develop understandings about NEAD storyline*

In comparison to the partner caregivers, these parents told stories which suggested that the diagnosis of NEAD offered them little relief or hope of making sense of their daughter's seizures and similar to many individuals with NEAD (Dickinson et al., 2010; Thompson et al., 2009), feelings of confusion were prevalent in their narratives, in addition to feelings of disbelief. In comparison to the partner caregivers whose partners typically experienced a shorter period of time between the onset of their seizures and diagnosis, the struggles in developing understandings that were reported by these parent caregivers may have reflected the prolonged period of chaos sustained by uncertainty that they experienced following the onset of their daughters' diagnosis; something which Whitehead (2006) hypothesised may "inhibit the ability to 'move on'" (p.2244).

Whilst these carers did not speak of believing that their daughter had been 'putting it on all along'; a reaction that Scheepers et al. (1994) noted was a common reaction from family members following the diagnosis of NEAD, their stories supported the suggestion that some caregivers may be as anxious about the diagnosis as individuals with the condition (Reuber & House, 2002). In particular, for these parent caregivers, the anxiety appeared to revolve around concerns about what the diagnosis meant in terms of their roles as parents. Similar to previous caregiving literature which points to

the common experience of parental or caregiving guilt, particularly in relation to caregivers blaming themselves for contributing to the development of the illness (Comaroff & Maguire, 1981; Harden, 2005; Milliken, 2001; Owens et al., 2008; Pejlert, 2001), the stories of these parental caregivers portrayed their difficulties in detaching themselves from feelings that they may have been to blame for their daughters' condition and disentangling the events from their 'identity' as a parent. Comaroff and Maguire (1981) offered an explanation for parental feelings of guilt in the context of illness and spoke about the 'identity' of children being "generally regarded as a function of that of their parents, who feel practical and moral responsibility for their well-being and their suffering" (p.119). Furthermore, they wrote that illnesses may be seen as an "assault on child rearing capacities…hence, the quest for cause and meaning in such illnesses is closely tied to the attempt to allocate responsibility for their occurrence" (p.119).

Deeply rooted in Western culture is also the assumption that mothers, in particular, are 'responsible' for the ways in which their children behave and develop (McNab & Kavner, 2001), probably stemming from the attachment story which often centers on the relationship between the mother/child dyad (Bowlby, 1969). With the majority of these parent caregivers being mothers and of White-British origin, it was possible that their meaning making and stories were influenced by these powerful narratives and that similar to those highlighted by Owens et al. (2008), some of their narratives were fundamentally 'moral narratives' which enabled them to illustrate to their audience that they had fulfilled their responsibilities, were 'good enough' parents and were ultimately powerless to control their child's destiny.

6.4.2   Living with NEAD and struggling to manage lifestyle changes

These parents also recounted parallel stories about the multiple changes that occurred in their lives following the onset of their daughters' seizures but in comparison to the partner caregivers, their stories depicted these as leading to a greater sense of 'biographical disruption' in their lives. The majority of the narratives illustrated how this sense of disruption was ongoing for many carers at the time of the interview. In comparison, Amanda appeared to anchor this in her past and her narrative suggested

that she had managed to create some distance, albeit a tentative one, from the initial disruption.

6.4.2.1 *Shifting sense of parental 'identity'*

Some carers spoke of a sense of their parental 'identity' shifting following the onset of their daughters' seizures (a shift that Milliken (2001) referred to as 'redefining of parental 'identity'' in the face of illness). For example, Henry spoke hesitantly of a perceived change in his sense of 'identity' from father to husband due to their increased proximity to one another in their lives and his daughter's reliance on his support:

> "I start to feel we're becoming like husband and wife, because I see so much of her and we do so much together. She's, she's going to a wedding...and I'm invited as well...so you know we're, we're almost seen as a couple. And I don't want that. There's something just not right about that, father and daughter shouldn't be seen as a, as a couple in the way a married couple would be...there's something uncomfortable about it".

Similarly, Sue said: "I've sort of become another carer...rather than a...a mum". For Sue, the shift from mum to carer appeared to bring with it a loss of control, as in comparison to her belief that mums "should be able to sort it", she spoke of struggling to "sort it...it...and that's sometimes when the tears come".

6.4.2.2 *Changing 'normal' trajectories of life*

Linked to these stories, parents spoke of a sense that NEAD had resulted in a disruption to the anticipated or 'normal' trajectory of the family life cycle and consequently to a fear of their disrupted futures.

For example, by emphasising the age of her children (which included her other daughter who also required some degree of care), Amanda orientated the listener to a possible perception that having to 'care' for 'older children' in the way she had to was not 'normal' and spoke about the disruption to aspects of her life: "I was quite tied

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with what were older children really. Everybody else was saying "oh we're going away"...I thought well I can't do that [laughs]". As discussed by Pillemer and Suitor (2002), it was possible that Amanda's story alluded to the conflicting demands that may be placed on parents of adult children, who both wish to help their children and be freed from their demands.

Sue also said "this is not what I expected [Lisa's] life would be". In particular the disruption to her daughter's work and social life appeared pertinent to Sue's narrative and something that she contrasted with the 'normal' life that Lisa experienced after her seizures reduced in the early days following their onset: "she was getting back to work...life was getting back to normal for her...normal things are happening, work, she's going out". Similarly Sue implied that it was not what she expected of her life: "like most parents, you think, oh when the children grow up, they'll fly the nest and things and you can get on with your hobbies...just being able to do what you want when you want". In comparison, she highlighted "I mean she's not completely independent of me" and spoke of anticipating that "unless things improve dramatically, I'm always going to be on call the rest of my life".

Finally, in the context of talking about her feelings of guilt towards the condition, Nicola shared her perception that her daughter "should be out there, you know, these are the best years of her life" and referred to ideas from "evolution....which just means...you have children, they grow up". This reference to children growing up, leaving home and gaining employment made me conscious as the audience that I may be of a similar age to their daughters and wondered whether as story-tellers they perceived that I may have a particular empathy because of my age, thus influencing the telling of these stories.

With their references to ideas such as 'flying the nest' and 'evolution', their stories appeared to point to the possible influence of dominant Anglo-American ideas of successful or 'good parenting' on their meaning making, being marked by a parent's ability to raise a child to independence and eventually separate from them (Gower & Dowling, 2008). As Atwood and Gallo (2010) wrote, "being diagnosed with a chronic

illness can lead...the...family into a feeling of normlessness, the social expectations have changed" (p.xiv). Similar to other literature on caregiver narratives, these carers portrayed that when an illness 'strikes' at the time when separation is anticipated and 'expected', this may evoke considerable feelings of loss for their own plans for life, in addition to the previously envisaged future for their family member (Harden, 2005; Milliken, 2001; Ramsay, 2010; Stern et al., 1999).

6.4.2.3 Changing relationships with daughter

These narratives also depicted a sense that parents' relationships with their daughters had changed since the onset of their seizures. In particular, similar to the partner caregivers, they told stories of a need to move closer to their daughters, often in an attempt to protect them from possible harm from seizures. However, in comparison to the partner caregivers, they told stories of struggling to manage this increased proximity to their daughters and to move again towards some level of independence.

Through her use of present tense, Nicola's story, for example, depicted the significance of the changes in her relationship with her daughter: "you're always never able to be completely normal". Similarly, when.speaking about her past, she referred to a sense that she was unable to have a 'normal' relationship with her daughter and referred to the dilemmas she experienced in knowing how much discipline was appropriate for her daughter when she was younger due to her fear that arguments or conflicts may trigger a seizure:

"I never felt I could discipline her that well...there were times when I thought if I shout at her she'll black out...and that, that was horrible, 'cos you just thought that any other teenager...you'll have a little argue, you know, girls and their mothers...very natural stuff...but things that are just everyday, but I could never have those".

As a consequence of her fear that arguments or conflicts may trigger a seizure, she explained that "We [i.e. her and her husband] really had to measure everything we said". By describing that "you're never able to be completely normal", she illustrated

the ongoing nature of this difficulty. Whilst she spoke of her perception that Anna "can't go through life in this, in this glass ball" and of her need to "let her [daughter] take responsibility for her own problem", she portrayed a sense that she had little hope that things would change in the immediate future: "I still can't quite let go of that needing to, to, look after her, 'cos you don't know".

Yet, through her story about her daughter's previous suicide attempt, Nicola pointed to the importance of this 'protectiveness':

> "And one time she did try to commit suicide, that was oh! That was, oh, that was terrible! Terrible. Because she couldn't cope with it anymore. So er, that was hard…there's a lot of times when she feels low, and I'm…worried…I have to fully support her so that she doesn't ever feel...she says she won't but I didn't know she was going to do it in the first place".

Whilst I recall the intense emotional atmosphere in the room when Nicola was speaking about this and noticed her subsequent evaluation of NEAD as being "a completely shit disease", she moved through this story rapidly, adding ironically: "so that adds another little dimension" when evaluating the event. The matter-of-fact and light-hearted tone in which she chose to tell this story and other stories in her interview was obviously important to her due to her explaining that "you've got to get a light-hearted, because otherwise it would just completely bring you down, completely. So you've kinda gotta make a joke about it, you know". However, I was also mindful that this approach may also serve to disguise the painful significance of some of the events that she spoke about. Perhaps connected to a cultural perception that gaining acceptance from others is often contingent on showing a positive front (Miczo, 2003), Nicola may have attempted to present a positive self-image to both gain my acceptance in the interview and to make her story more bearable for others to hear and possibly, for her to tell.

Finally, perhaps as a consequence of her constant need to protect "this glass ball", Nicola also alluded to the impact of the 24-7 nature of her caregiving role on other

members of their family. In particular, she spoke of her concern that her "poor husband is real bottom of the pile because I, you know, daughter comes first because she's needy, son comes second...and that affects the family". Connected to the concept of guilt that has been highlighted in previous sections of this storyline, this story suggested that for Nicola, she may have felt a sense of responsibility for the family disruption and experienced a conflict in terms of where and with whom she should allocate her resources and time. This has been reported by other caregivers in the literature (Milliken, 2001; Ramsay, 2010).

Henry's story also portrayed the changed relationship with his daughter. For example, in response to the opening question, he referred to a sense that he was always on call and spoke in the present tense about his daily life 'revolving around' his daughter Helen: "my life revolves around her...I'm only looking at the running around I've got to do for Helen". He spoke of feeling "tied down" and "lacking freedom", and also alluded to the "blindness" of it all, which he attributed to his reason for forgetting about and thus arriving late to the interview. Despite the continuing nature of his difficulties, he told a brief story that suggested that the distance between him and his daughter may widen again in the future. For example, in response to a question about his future, he recounted a story about recent occasions where he had made a "specific effort" to encourage Helen to do things without him. He attributed this to his hope that "I want my own life [and] to prise us apart to some extent".

Furthermore, whilst Sue referred to her increased freedom since her daughter had moved out of home: "I can go out when I want", she explained "but I'm not started to relax more" and explained that she always had her mobile "stuck to" her incase her daughter needs her after a seizure. She reinforced the 'on-call' nature of her relationship with her daughter by orientating our attention to the interview context: "I've come out...so my brother's on call". She further illustrated a change in their relationship when she depicted a sense that she has to hide her emotions from her daughter and put a "brave face on and not...not let Lisa know that I'm quite...well quite down about it, you know". As in the context of the interview, this was perhaps facilitated by the stories she told about herself as being a "coper": "I think I've

managed exceptionally…I've coped the best I can. I am a coper" and a 'good carer' (Pickard, 2010), illustrated through a story she told in a proud tone about having "saved the Health Service a lot of money" reflecting discourses about the important role that informal caregivers are intended to play in saving money for society (Pickard, 2010).

In comparison to Sue, Amanda's story suggested that when her daughter "finally went to live on her own", this enabled her to create some distance from the initial disruption to their relationship. However, whilst she described herself as starting to "relax" a bit and rely on her daughter's boyfriend to support her during a seizure, her story illustrated the tenuous nature of this change and highlighted that in many respects, her worries were ongoing: "you know every time the phone goes you do think is it. And she has a um...", with the unfinished sentence perhaps an illustration of a fear of the unspeakable.

6.4.2.4 *Changing working lives: from employee to caregiver*

In recalling her past, Amanda, in particular, recalled the disruptive impact of her daughter's seizures on her working life. For example, she described having to take up a part-time job that she "didn't like…I hated the job [laughs]", in order to be more available to support her daughter and recalled feeling "resentful" that she had to make this change. Perhaps to justify this feeling, she appeared to draw me in by saying "well, me children are older…you know I'd looked after them when they were younger and I thought, now, it's my turn now and I couldn't". In telling this story, it was possible that she felt guilty about sharing a negative feeling about her parental role; perhaps influenced by societal ideas about parents always having a 'moral responsibility' to care for their children (Harden, 2005). Furthermore, she continued by saying that "I couldn't really do that [i.e. continue with her full-time work] cause my husband worked away a lot" and through the telling of this story, she appeared to suggest that she had no choice but to remain within the confines of traditional gender expectations about who *should* stay at home to care for their children.

6.4.3 Encountering others and struggling to manage their sense making of NEAD

Similar to the partner carers, these parents told stories about encountering the misunderstandings and critical judgements of others. However, their narratives suggested that they struggled to a greater extent in managing these reactions. Like some of the partner caregivers, all these parents started to tell these stories in response to my question about their motivations for taking part in the interview and these stories were often told in frustrated tones and with emotional language. Therefore, whilst these stories were co-constructed in response to my question, they suggested that many of them came to the interview with an active and political agenda of their own (Miczo, 2003); to call for action and raise awareness of the condition and their experiences of it. It was possible that the friends and family, general public and medical professionals that they spoke about were the 'ghost audiences' (Riessman, 2008) of their narratives, to whom they wished to direct their stories.

6.4.3.1 *Encountering misunderstandings*

Amanda, for example explained that "when I talk to people it's, "Oh..." They just don't...[laughs]...How you can call it...how can it be non-epileptic but the seizures are..." and when I followed this up with a question later on in the interview, she described that she tended to avoid having conversations about NEAD with others: "I don't talk to people much anyway. I just say Mary has these seizures that aren't epilep [laughs]". Drawing on research which suggests that laughter or humorous references can enable people to talk more easily about uncomfortable topics (Emerson, 1973, as cited in Glenn, 2003), it was possible that Amanda's laughter during the interview mirrored the interaction style that she typically adopts when trying to explain to others about a topic that she finds confusing and uncomfortable to talk about, i.e. the nature of her daughter's seizures. Sue also referred to the lack of understanding of others in the opening lines of her narrative and depicted a more significant struggle through her use of broken sentences and sighing, in explaining the condition to others: "I...and try to get people un...to understanding that it's [sighs]...I don't know whether you'd call it an illness. Um, yeah, I suppose it is an illness isn't it?" Through this latter question where she appeared to be looking to me for epistemological validation, she illustrated

that this explanatory struggle for her may have also paralleled her ongoing struggles in developing an understanding of the condition herself.

Sue also spoke about the "ignorance" of the medical professionals and Amanda recounted in an angry tone about how she had never met "one A & E doctor who actually knew what it was". Whilst Amanda spoke of struggling to stand up to the medical professionals and challenge their misunderstanding, she re-played a number of arguments between her daughter and doctors over the fact that she had NEAD and not epilepsy. Perhaps to intensify the emotional and continued significance of these events for her, she appeared to dramatise them by giving speaking roles to each character: "The doctor... "Oh no, no, you must, it's epilepsy." And she said, "No, it's not epilepsy, it's this NEA..." "... well [laughs] he didn't und...He just...and the nurses don't". Ironically, she highlighted in this story the apparent role reversal with her daughter having the 'medical' expertise and taking an active role in relation to the misunderstanding of the doctor. In comparison, Nicola explained that after a number of arguments with medical professionals over the misunderstandings of her daughter's seizures, "in the end we lied and said it was epilepsy", thus telling a story of colluding with the medical ignorance in an attempt to minimise negative interactions between themselves and the medical professionals.

6.4.3.2 *Encountering critical judgements*

Parents also spoke of encountering the critical judgements of others. For example, Henry said that his other children were "fairly ambivalent and um, there is an element of, oh just get on with it...type of thing". Sue also spoke in a frustrated tone about the dismissive attitudes that she perceived her daughter had been exposed to from medical professionals, including perceived judgements such as "You're a fraud. You're putting it on. You're attention seeking".

Perhaps as a consequence of the condition and subsequently their role and status as carers being doubted by other people in society, the narratives of some of these carers suggested that they may have come to the interview with an expectation that I too may have judged their stories critically (De Fina, 2009). For example, in the opening

section of her interview, Sue appeared to demonstrate a need to justify her daughter's condition and engaged with her audience by saying "but I'll assure you, if she could pull herself together and stop it she will, you know". She followed this with a rhetorical question, "why treat her as though she's something that's um making it up or putting it on?" but instead of waiting for an answer, perhaps in an attempt to protect herself from possible criticism, she followed this with: "I mean why would anyone you know purposely sort of....I mean she's banged her head and grazed her knee...it's just halted her life". As discussed by De Fina (2009), the inclusion of the discourse marker 'I mean' at the beginning of sentences may signal uncertainty and thus, may be suggestive of Sue's continued ambivalence about the nature of the condition.

Henry told a number of similar stories but also seemed to constantly draw me into his narrative, at different stages, with phrases such as "well, you're much nearer to fifteen than I am" and "I'm sure you know what I mean". These phrases may have suggested that he perceived me as an ally to his story and as someone who was able to validate his story due to being of a perceived age which meant I could understand his and his daughter's shared experiences. By warning me that he may "occasionally use the wrong term" when referring to my role "because psychiatrists, psychotherapists, psychoanalysts, I'm, I'm not sure of the distinction", and positioning himself as needing to be "careful" in doing so, he also appeared to illustrate a sense that he didn't want to lose me as an ally to his story and my understanding.

It has been argued that chronic illness can lead to a loss of social status (Miczo, 2003) but when a condition falls outside the dominant Western medical discourse, it may be even harder for individuals to maintain their status as 'patient' and for society to give permission to allow individuals to be legitimately ill and to take up the 'sick role' (Parsons, 1975). Narrative is thought to play an important role in enabling 'patients' to regain lost status by justifying his or her own actions (Riessman, 1990) and through their narratives, these carers appeared to be suggesting that they too, may have perceived that their status as carers was doubted by others and were using their narratives to regain this status and a sense of understanding from their audience.

6.4.3.3 Encountering support from others

Whilst many of these stories were co-constructed in response to direct questions from me, stemming from my assumptions about the benefits of support from services and my expectations that there was likely to be little support for carers, most carers recounted stories about the lack of support from healthcare professionals and appeared to share a sense that individuals with NEAD have reported being "left in limbo land" after the diagnosis (Thompson et al., 2009).

6.4.3.3.1 From family and friends

In comparison to the partner caregivers, many parents described feeling isolated in a society where people appeared to misunderstand NEAD. For Amanda, she presented this as being an ongoing experience by using both past and present tense: "so you were very much on your own with it" and "so yeah, it's very isolating, I say it's isolating that's how I felt".

Henry and Nicola also illustrated a sense of isolation and in particular appeared to present as lone figures throughout their stories. For Henry, he connected his feelings of isolation to the lack of support from others: "completely isolated...there's no one else giving her any sort of support, apart from me". In comparison, Nicola connected her feelings of isolation to the fact that "you didn't feel that anyone understood you. You just thought, well, my friends must think I'm mad, so you didn't tend to talk about it". Bringing this story into her present, she continued to explain that "it's really hard to talk to people about it, therefore you don't, you just keep all your feelings inside". Perhaps as a consequence of these experiences, the interview may have provided Nicola with a rare and useful space to talk about her experiences and may have offered her a route to a space where her story may be given more authority and more weight, i.e. if it reaches a 'medical journal': "if your report does get documented and it does end up in a medical journal, other people are going to understand and more aware".

Without the opportunities to talk to others about her experiences, Nicola spoke of being left with "this bubble of emotion just below the surface all the time...it's never

really left, the 6 years of, living with it". Whilst she began her story with "it sounds like selfish like you want more atten...", suggesting that she may have been worried that I may have perceived her as a complainer, she also spoke in an angry tone about her perception that, unlike a friend of hers who was caring for her father with Alzheimer's disease and receiving a lot of support from others, "no one would look at my problem and give me the same". She attributed this to the idea that NEAD is "not diabetes, it's not, it's not the things that are recognised when people go 'oh poor you' and can understand" and perhaps implicitly to her sense that NEAD is perceived by others as a condition that is not 'worthy' of support. Her narrative pointed to the challenges that caregivers may face in reaching out for support that is not readily available, in particular when they may be influenced by Western ideas that value individualism and personal responsibility (Travers & Lawler, 2008).

Despite these stories, carers illustrated that certain individuals appeared to offer valuable emotional and practical support to them, highlighting the moderating effects that social support can have in the disruption caused by caring (Brown & Harris, 1978, as cited in S. Williams, 2000). For example, Sue identified that certain family members had given her "the strength to, you know, sort of cope with it, I suppose", whilst Amanda referred to the support that she received by some individuals, such as her daughter's partner, stepping in to take over some of the caring roles.

Similar to the partner caregivers, they also spoke about the NEAD Trust playing an important role in their lives. In particular, Nicola spoke of being able to gain some perspective on the severity of her daughter's seizures by hearing about other people's seizures through the charity websites: "that was an eye-opener, because seeing the website was like wow! Really! If you scaled a NEAD sufferer from one to ten, Anna's probably three or four...so Anna actually is quite lucky". Learning about and meeting other people with NEAD was also a key story recounted by a number of carers. For example, Nicola spontaneously recounted a time when she had learnt from Anna's specialist that there were other people "like Anna" and her use of positive language and upbeat tone when telling of her reactions to this, such as "it was amazing!" and "you think, God, 100 people", in addition to giving the doctor a speaking role in her

story, suggested the significance of this event for Nicola. Kyriacou (2010) wrote that feelings of isolation that caregivers often experience may be connected to them not seeing "themselves as members of any group" (p.169) and thus finding other caregivers who were managing similar difficulties may have helped caregivers to, as Kyriacou (2010) wrote, begin to reconstruct "that view to one that identifies them as members" (p.169) of a community.

6.4.3.3.2 From health services

Carers also spoke about the lack of support they received from services. For example, Amanda said that the family "are just, you know secondary" to the individual with NEAD and explained that due to the lack of information about NEAD for carers, "you have to muddle through as best as you can". Sue also said that, "there wasn't a lot of support...there isn't a lot of support...that's what I feel anyway. So...I'm sorry but [laughs]...that's how I feel". Through the laughter and tentative way of telling this story, it is possible to infer that her story was muted or underplayed by her perception of my position as a healthcare professional. Furthermore, carers spoke of their frustrations about the "postcode lottery" in relation to the support available for NEAD in the UK, and the lack of clinic facilities, which Nicola compared to other health conditions: "like you know, diabetes, there's a diabetes clinic, there's that, and they take it onboard as a, a serious illness".

Whilst positive stories about their encounters with medical professionals appeared minimal, the few stories that they told were typically characterised by responsive medical professionals who were sensitive and open to discussing NEAD. For example, Sue recounted a story about a member of the ambulance service giving her some helpful techniques and advice to manage her daughter's seizures. She also spoke of valuing the ongoing support that she receives from her GP: "Although she…she'd never heard of it…she was lovely…she used to come, you know and just sit and that. And odd times she'll ring up if she hasn't seen us or heard from us for a while and just make sure that I suppose I'm alright and coping and that, you know Lisa's alright…she is lovely".

6.4.4   Summary of stories of 'biographical disruption'

In summary, these carers told stories which illustrated a struggle to reconstruct and move away from the initial disruption following the onset of their daughter's seizures. Through their stories, they spoke of their difficulties in making sense of their daughter's condition and the changes that occurred in their lives and depicted caring as representing a form of 'biographical disruption' on their lives. They also portrayed a sense that they struggled to negotiate and respond to the misunderstandings and judgements of others in society, which often left them feeling isolated. Similar to Frank's (1995) 'chaos' narratives, their stories depicted a sense that they experienced a lack of control within the context of the condition and imagined life never getting better.

Thus, these findings support the literature which suggests that when individuals are unable to place illness within the context of one's life, this can induce profound changes on self image and 'identity' issues (Whitehead, 2006). Similarly, Carton et al. (1999) found that when individuals with NEAD struggled to develop an understanding of the condition, this was found to have a negative impact on prognosis. Through their stories, they illustrated their difficulties in disentangling feelings of responsibility for the condition due to their parental relationship with their daughter, which appeared to impact on their meaning making. It was possible that the short length of time between the diagnosis and the interview for two carers may have influenced their meaning making and the stories they told. Yet, two partner caregivers experienced a similarly short length of time between the diagnosis and the interview and it is possible that in comparison, the struggles depicted by the parent caregivers may have been connected to the considerably longer length of time between the onset and diagnosis of their daughter's seizures (for three carers, this ranged between 4.5 years and 12 years), in comparison to the length of time experienced by the partner caregivers (which ranged from between 2 months and 4 years). Finally, with the majority of the parents being female caregivers, as with the partner caregivers, it was also possible that gender factors influenced the stories that these parents told.

7 Summary of findings

This study has explored the stories told by eight family caregivers of adults diagnosed with NEAD and has attempted to address the gap in knowledge in this area. As highlighted in the previous chapter, the findings from the study support a number of previous findings from the literature surrounding NEAD and caregiving and contribute new information to add to current understandings. In the following section, I hope to provide an overview of the key findings from this study and consider these in relation to the current social, political and cultural climate. I will subsequently consider how these may point towards recommendations for clinical practice and future research. The methodological considerations of the research will also be discussed.

7.1 <u>Overview of the findings in context</u>

Pertinent to all narratives in this study were parallel and ongoing stories about carers' understandings of NEAD, their responses to lifestyle changes and to the sense making of others towards NEAD. Their narratives reflected a sense that negotiating their new role as a caregiver for their partner or daughter with NEAD was a complex task, challenged at times by the influence of often competing social and cultural narratives. Furthermore, the stories they told on the day of the interview differed in that some narratives worked to position their caregiving role as being a form of 'biographical continuity', whilst others worked to position it as being a form of 'biographical disruption'.

7.1.1 Sense Making and NEAD

All carers depicted the onset of their partner or daughter's seizures as being an emotional experience and in particular, a lot of their stories focused on the distress resulting from the lack of medical certainty about the nature of the seizures and their initial sense of confusion of how seizures (i.e. a physical symptom) could be caused by a possible psychological cause, rather than a purely biomedical cause. These experiences could be seen to be reflective of the influence of the dominant biomedical

discourse in Western society, which posits that illnesses typically have a biomedical cause that can be objectively identified by medical professionals and subsequently can be treated.

It was interesting to notice that over time, the majority of the partner caregivers spoke of their developing understanding of the likely psychological factors underlying their partner's diagnosis of NEAD. In comparison, all the parent caregivers spoke of the feelings of confusion and disbelief that they experienced following the diagnosis and told stories which suggested that they worked hard to resist the psychological explanations of NEAD and to seek out alternative medical explanations for their daughters' diagnosis. The significance of finding a medical explanation for their daughters' diagnosis was highlighted by their concerns that without such an objective cause, the 'reality' of their daughters' condition may be judged by others. In comparison to the partner caregivers, the narratives told by the parent caregivers were often replete with references to discourses about the negative connotations of psychological conditions or 'contentious conditions'; often perceived to be lower down the 'hierarchy' of illness (Nettleton, Watt, O'Malley, & Duffey, 2005).

This hierarchy of illness is typically bound up with ideas relating to mind-body dualism which posits that the mind and body function separately to one another. Thus many of their concerns focused on whether their daughters may be perceived as being responsible for their seizures i.e. being a 'fraud', an 'attention seeker' or someone who is 'putting it on'; or whether they would be perceived as perhaps being indirectly to blame for their daughter's condition. Through the proximity of the phrase 'why would your body do that to you?' to talk about 'pseudo' and 'faking' by one mother, there was a sense that perhaps some caregivers also questioned or were uncertain about the 'reality' of their daughter's condition, thus impacting on their developing sense making.

7.1.2   Encountering the sense making of others

In addition to negotiating their personal sense making of NEAD, their stories also highlighted the challenges that they experienced in responding to the sense making of

others towards NEAD i.e. the misunderstandings and critical attitudes of others, in addition to the availability of support from society, family and friends. How participants positioned themselves in relation to the dominant medical discourse and talked about their partner or daughter's condition was of interest in this study; both in the context of the interview setting and in terms of how they spoke of communicating their understandings to family members, friends, medical professionals and the wider public.

For example, two of the partner caregivers, namely Sarah and Robert, appeared to position themselves away from the dominant medical discourse and gave coherent accounts of a counter-narrative (Jones, 2002) i.e. that NEAD can be understood within the context of the interaction of psychological and physical factors. However, with a condition that does not automatically afford social status as a recognised 'illness' in society, their narratives highlighted a sense that they had to work hard to establish and maintain their position. In particular, they highlighted the importance of gathering information to enhance their understanding of NEAD, which ultimately helped them to develop a clear explanation to inform other people about the nature of NEAD and to equip them with information to fight or argue against negative judgements that they perceived they may encounter. Whilst they spoke in confident tones and described themselves as constantly adopting an assertive position when encountering others to ensure they gained their understanding and support, it could be inferred that by implication, the perhaps precarious nature of their position left them with little space to reflect on and demonstrate any sense of uncertainty in their accounts.

In comparison, whilst the two remaining partner caregivers aligned themselves to the possibility of a psychological explanation for their partner's condition, their narratives reflected a greater sense of uncertainty, perhaps influenced by the position that one caregiver took in terms of leaving the understanding 'to the experts'. This appeared to leave them in a more overtly precarious and troubled position and both of their stories reflected struggles in explaining the condition to others. In an attempt to manage this, they spoke of their tendency to either minimise the condition in an attempt to avoid conversations about NEAD or to align NEAD with an equivalent or similar 'medical'

condition such as epilepsy, perhaps in an attempt to seek cultural 'legitimacy' through linking NEAD with existing medically sanctioned conditions.

In contrast, without the presence of a medical explanation as yet, the narratives of many of the parent caregivers suggested that they were required to work hard to convince others of the legitimacy of their daughter's condition and of their required status of a caregiver. Yet there was a sense that this task was made harder by the perceived lack of understanding of the condition and persistent doubt about the nature of the diagnosis for some caregivers. Furthermore, similar to the findings of participants with CFS in Werner et al's (2004) study, their stories also highlighted that their experiences were complicated by the existence of some paradoxical ideas, namely that they didn't want to appear as though they were complaining too much in an attempt to 'seek attention' and wanted to preserve a positive self image. As such, many spoke of either avoiding conversations about NEAD, not telling their friends about their difficulties or mis-representing the nature of their daughter's condition, e.g. telling others that their daughter had epilepsy. As discussed by authors such as Album (1996, as cited in Werner et al., 2004) and Werner and Malterus (2003), it was possible that many of these caregivers were influenced by narratives about the rules about how to talk about illness in today's society, including the narrative that 'patients' should not complain or make a fuss. Furthermore, Frank (1995) discussed that restitution stories about illness i.e. the idea that we get an illness, get it treated and recover, are among the stories that are valued in Western society. Thus, with a condition such as NEAD which does not fit with this normative expectation, it was possible that many of these caregivers found it harder to accept their stories and thus assertively relay these back to their wider social context.

7.1.3 Responding to lifestyle changes

Parallel to these stories, carers spoke about their responses to the lifestyle changes that they had experienced since the onset of their partner or daughter's seizures and their attempts to make sense of the changes that the condition had made in their lives. For partner caregivers, in particular, their narratives suggested that they had found a way of making sense of and managing these changes by perceiving their caregiving role as

something which was an 'expected' part of their long-term commitment to their partner; thus depicting it as a form of 'biographical continuity'. In comparison, the narratives told by the parent caregivers suggested that their new role created a greater sense of 'biographical disruption' perhaps due to it occurring at a time in their lives when they were hoping to and were 'expected' to 'let go' of their parental duties, and thus their stories depicted greater struggles in managing the lifestyle changes that they had experienced.

The narratives told by the caregivers in this study suggested that many of them were faced with conflicting narratives to negotiate, in particular social narratives around parenting and caregiving. All of the parent caregivers spoke of their feelings of unease towards the diagnosis of NEAD and of their feelings of guilt and the perception that other people, including medical professionals, may blame them for the cause of their daughter's seizures. These stories could be seen as reflective of wider societal and political discourses, which hold parents and particularly mothers, accountable for their child's moral development and their roles in raising a child who is healthy and can successfully contribute to society (Comaroff & Maguire, 1981; McNab & Kavner, 2001).

Their narratives also suggested that many of them were influenced by conflicting discourses about how they should parent and support their adult child with NEAD. On the one hand, with their daughters all experiencing their first seizure between their mid-late teens and early twenties, the narratives told by the parents illustrated that they were not impervious to the Western societal expectation that their children should be leaving home at their age and separating from the family unit and that they, as 'good parents' should be encouraging them to do so (Gower & Dowling, 2008). However, their narratives also highlighted that whilst many of them wanted to encourage independence to certain degrees, they were additionally influenced by fears about their daughter's safety when having a seizure in their absence and their desire to protect and nurture their child. As highlighted in their stories, this led to a complex re-negotiation of their own and expected future stories and their identity as a parent. For one mother in particular, this involved a shift from defining herself as a mother to defining herself

as a carer, perhaps reflecting her expectation that her caregiving role would transcend into the future and be life-long.

The influence of discourses about being a 'good carer' (Pickard, 2010) were also evident across the narratives of both parents and partners. For example, whilst it was likely that parents felt influenced by the expectation that their child should be separating from them due to their age, it was likely that they also felt influenced by the socio-political pressure applied to family members, that they should care for their family members in order to support 'the Big Society' (DOH, 2010). As a consequence, this expectation meant that many of the partner caregivers had to adjust or give up their work to be at home to care for their partner, thus impacting on what many of the male caregivers may have traditionally perceived as their role to 'provide' for the family. With the role of 'caregiver' traditionally being allocated to females (Starrels, 1994), research suggests that male caregivers may approach care work in ways that create and sustain feelings of masculinity (Calsanti and King, 2007; Russel, 2001). This was evident in some of the narratives told by male partners, in particular through their references to using strategies such as distancing themselves from emotions or minimizing the care work's disruptions on their lives.

7.1.4   Summary

In conclusion, this research illustrates that all caregivers of adults diagnosed with NEAD experience a range of disruptions in the context of their lives and supports previous research which suggests that the experience of caring may either by coped with through a strategy of 'biographical continuity' or may involve a greater sense of 'biographical disruption' (Adamson & Donovan, 2005; Chamberlayne & King, 1997).

In comparison to previous research by Krawetz et al., (2001) who found that the responses of the family members of adults with NEAD did not differ on standardised questionnaires in regard to the role (i.e. spouse, parent) they assumed in the family unit, the findings from this study point to differing stories being told by partner and parent caregivers. Furthermore, this research highlights that within the context of diagnosis such as NEAD, many caregivers are required to negotiate often conflicting

and competing discourses about mind-body dualism, parenting, gender and caregiving. As our 'identities' are always narrated within discourses and tied to power relations, many of their stories served to highlight the challenges in integrating their new roles within the context of such ideas. As Kyriacou (2010) eloquently wrote:

> Believing that the role they play in society is commonly understood, respected and valued, will help caregivers make a healthy transformation to a caregiver self…if the larger social community…can show respect for and attribute value to the caregiving relationship, the caregiver can more readily accept the new 'identity' and integrate it into their existing 'identity' (p.169).

Thus, the findings point to the importance of health professionals and services being aware of the challenges that many caregivers may face on an ongoing basis and their potential need for support in making sense of the influence of such narratives. Due to the many challenges that caregivers spoke about throughout their narratives, the findings of this study indicate the importance of thinking systemically when developing interventions for individuals with NEAD.

7.2   Recommendations for practice

The findings of this study point to a number of important recommendations for practice.

7.2.1   A whole-family approach

The findings suggest that caregiving can have widespread emotional and lifestyle consequences for carers within the context of NEAD. These findings support the recommendations in the DOH Carers Strategy (DOH, 2010) for providing ongoing support for carers and Atwood & Weinstein's (2010) advice that medical practitioners working with individuals with chronic illness "need to embrace families in their treatment of illness and expand their perspective from an individual medical model to a social systemic model" (p.54). Furthermore, whilst more research is needed, the

carers' stories alluded to the wider impact of NEAD on other family members, thus pointing to a whole family approach where appropriate.

Similar to other research with caregivers (Stern et al., 1999), the findings of this study particularly point to the importance of sense making in shaping carers' experiences and highlight that many carers are faced with an ongoing struggle to develop understandings about the condition and manage the feelings that are raised by this process. In line with evidence that suggests that outcomes for individuals with NEAD can be improved by a successful communication of the diagnosis (Reuber & Elger, 2003), the findings that some carers struggled to understand NEAD point to the active role that services and health professionals could take in providing space for carers too, to talk through their idiosyncratic sense making of the condition. This would be in line with the recommendations proposed by Thompson, Osorio and Hunter, (2005) in their protocol for the communication of the diagnosis.

This process would be facilitated by adopting a neutral, collaborative and curious stance (Cecchin, 1987), in addition to conveying an acceptance that the cause of some aspects of the condition may never by fully understood (Watson & McDaniel, 2000). Moreover, moving from 'Either-Or' to 'Both-And' thinking i.e. moving away from thinking of symptoms as being either psychological or physical to thinking of symptoms as both physical and psychological (Watson & McDaniel, 2000) may also facilitate this.

The findings indicate that support may be beneficial for the caregiver at multiple and ongoing points of their lives, including following the onset of their partner or daughter's seizures, at diagnosis and as they experience changes to their lifestyles and relationships. In addition, the findings point to the possibility that some carers may benefit from having space on their own to explore their feelings and meanings behind their caregiving role. Where appropriate, Narrative Therapy, with its focus on inviting stories of resourcefulness and alternative understandings (White & Epston, 1990) may be helpful. Paying attention to the influence of biographical, cultural, generational and gender factors may help to ensure that understandings are formulated in context.

7.2.2 The importance of support groups

In their interviews, all carers pointed to the importance of receiving informal support from family, friends and people with whom they have some shared experiences. In particular, they emphasised the importance of the NEAD Trust support group and spoke of its role in providing opportunities for them to talk to other people going through similar experiences and access information and practical advice about aspects relating to the condition. Thus, these findings illustrate the vital role that voluntary services can play in offering carers support, particularly when they may struggle to talk about the condition with family and friends, who may lack the understanding of NEAD. The findings therefore reinforce the need for this provision to be prioritised so that it is available to caregivers and for it to be developed further so that it is more accessible for people across the country.

7.2.3 Service related recommendations

In their interviews, many carers referred to the lack of support for family caregivers and spoke of feeling excluded from or "secondary" to the care that the individual with NEAD received. Some carers also contrasted this lack of support to other medical conditions and emphasised the 'postcode' lottery that they had experienced in terms of accessing support. These findings point to the importance of policy documents being developed that are specific to NEAD and which address the support needs of carers and individuals with NEAD. In doing so, the findings point to the importance of considering the terminology used in policy documents and by services who aim to target 'carers' to ensure that 'caregivers' who may not define themselves as such are aware of the provision that is available to them.

The findings also highlight the role that services and professionals can play in increasing the understandings of others, both in the wider public and within the medical profession. In relation to other conditions, Scott (1994) has advocated that the media could be used to access wider audiences and disseminate information. It is interesting to note that there is no mention of NEAD on the website Healthtalkonline (Health Experience Research Group, n.d), which is a charity website that includes videos and personal stories of different illnesses and health conditions and thus may

be a useful forum to access in the future. Finally, the findings point to the need for training programs about NEAD to increase the awareness of the condition amongst the medical community and social services. This was a particularly important point emphasised across all of the narratives and was re-iterated by the three caregivers who responded with some reflections about the findings of the research. In particular, they wrote:

- "I am pleased that you have recognised the need for the medical profession to take more interest in NEAD" (Amanda)

- "knowledge is what is needed, and good experts to help" (Nicola)

- "the most vital point is getting health professionals to understand and recognise that people with NEAD are not...putting their seizures on to attract attention...If this could be resolved, I am sure many sufferers would feel that they were not wasting medical professionals time and be treated with understanding" (Sue)

7.3   Strengths and Limitations of the study

The qualitative approach applied a new lens through which to consider the storied experiences of caregivers of adults with NEAD and I believe that this was a particular strength of the study. The narrative approach also enabled a detailed analysis of the stories told and the storytelling, in addition to enabling the stories to be situated in their local and wider contexts. As with other qualitative approaches, it could be argued that due to the subjective nature of interpretations, stories are liable to misinterpretation by the researcher. However, I would argue that there are always multiple interpretations, which are all valid. Furthermore, out of the three participants who responded with some reflections about the findings of the research, all of them commented that the findings were reflective of our conversations during the interview: "the findings are interesting" (Sue), "[the findings] are very valid" (Nicola) and "your summary is spot on" (Amanda).

I believe that a further strength related to the sampling process which gained participants from a range of geographical locations, which has been lacking in previous research in this area, and with a diversity of caregiving experiences. Whilst I was not intending for the findings to be generalised, the findings are limited to this particular small group of carers, who all care for women with NEAD and are all of Caucasian and Western origin. Furthermore, the sampling was non-random as participants volunteered for the study (and thus may be limited to carers who are motivated to verbally express their experiences) and all of them were already connected to a 'community'. Although the findings may resonate with other carers, it is unknown whether similar stories would be told by carers from other cultural groups, carers of male adults diagnosed with NEAD and those who are not connected to the support group from which participants were recruited.

Moreover, it could be argued that the interview format used in this study was a limiting factor as it required verbal language as the channel of communication and thus relied on the verbal abilities of participants. Interviews have also been criticised for inviting a particular type of talk and multiple modalities may have provided space for storying through other means which may have revealed different stories (Lawton, 2003). In addition, due to the timeframe, this study captured participants' stories at one point in time and ideally multiple interviews, which is preferable when studying biographical experience (Riessman, 2008) would have enabled a more in depth focus on how carers' experiences may be narrated differently over time. Whilst this was originally intended, it could also be argued that I did not collaborate with participants in the development of the study and hence an improvement of this study could be to work with participants from the outset to ensure the research is informed by the needs and aims of the community (Gergen & Gergen, 1997).

Finally, my decision to exclude the stories of two participants in this thesis i.e. the friend and the parent-couple was something that was not made easily and could be critiqued due to my decision to privilege some participants' stories over others. However, based on the differing nature of the friend's relationship and of the couple interview, I felt this was an appropriate decision to make and have drawn on

preliminary findings from their interviews when making recommendations for future research.

7.4 <u>Suggestions for Further Research</u>

The ultimate test of validity for qualitative research according to Riessman (2008) is whether a piece of narrative research becomes a basis for others' work. In line with my discussions above, I believe that my study has highlighted a number of possible avenues for future research to explore.

In particular, I recommend that this area would benefit from further research that includes a more diverse group of carers, meets participants multiple times and uses a variety of methods of data collection to provide different means for participants to tell their stories. For example, Funk and Stajduhar (2009) wrote that observational research, combined with interviewing may contribute to a more detailed exploration of caregiving experiences. The findings of this study also indicate that there may be possible grounds for a fruitful and more detailed follow-up use of Discourse Analysis as well as Foucaldian narrative analysis, to look more at how medicalised power and context shape narratives, especially around experiences that are as yet medically ambiguous or contentious.

Finally, the findings suggest that the experiences may differ depending on the nature of the caregiving relationship with the individual with NEAD. Preliminary readings from the interview with the friend-caregiver highlighted that he frequently spoke about the challenges he faced in hearing personal and distressing information about the possible factors behind the diagnosis of NEAD for the person he was caring for and in particular, spoke of feeling unable to talk to and "offload" onto others due to being outside of the family. However, at the same time, he explained that this sharing of information meant that he developed a closer relationship with his friend.

The findings of this study also suggest that the experiences may differ within the same family i.e. amongst parents, grandparents and children. Particularly where different opinions exist, this raises questions about how meanings and in particular, ambiguous

illness meanings, are negotiated within families. Preliminary readings from the interview with the parent-couple reflected how many of the stories and meanings were co-constructed in the interview setting, by each couple completing sentences for each other. In particular, their interview also highlighted the different emotional responses shared by each parent caregiver towards their caregiving role and the importance of working together to 'cope'. Many references were also made to the overall 'family coping' approach. To widen understandings about the caregiving role within a family unit, research that focuses on parent-couples or includes multiple family members may be important in the future to further inform service provision which aims to meet the needs of all family members of individuals diagnosed with NEAD.

8 Concluding remarks: An ending

Start with a story of one individual and the first seizure; then stories of months or years of further seizures and uncertainty and finally to the story of the diagnosis of NEAD. But this is not the end of the story: it is simply the opening paragraph of a long narrative, with some told and some untold stories, of the many lives which have been affected by that first seizure.

This thesis has focused on the stories about change and disruption to all these people, such as parents and partners, whose lives will never actually be quite the same again. It now needs readers; not only readers but good listeners who hear again and again in the stories that caregivers are still seeking answers, still seeking understandings and still seeking support. If these stories are really listened to then, as Ellis (2007) wrote, this will "leave the communities [and] participants... better off at the end of the research than they were at the beginning" (p.25).

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10 Appendices

10.1 <u>Appendix A: Literature search strategy</u>

In completing the literature review chapter, electronic literature searchers were conducted on all the major psychology, social science and medical databases, including PsychINFO and Pubmed over a period of 16 months. To complement the database search, specific journals were searched for research on NEAD including *Epilepsy & Behavior*, *Epilepsia* and *Seizure* and for qualitative research including *Qualitative Health Research* and *Narrative Inquiry*. Furthermore, literature was also identified from reference lists of relevant articles/books, through consultation with academics and clinicians in the field and using the Google search engine (Google Scholar). The key words identified by the authors of the most relevant articles guided the use of some of the search terms and a number of editing procedures[13] were also used to expand the searches. Due to the myriad of labels for NEAD, I will outline only a few examples of search terms that were used in combination. These included: non-epileptic attack disorder, psychogenic seizures, dissociative seizures, parent, caregiver, family, significant other, impact, experience, coping and qualitative. Both conceptual and empirical studies were considered.

Given the paucity of literature available on the experiences of caregivers of people with NEAD, studies on the experiences of caregivers of people with chronic illness, in particular medically unexplained symptoms were included. I was mindful of the generalisability issues associated with this. With this in mind, specific journals were also searched for research on family issues and meaning making in chronic illness including *Family Practice*, *Families, Systems and Health* and *Sociology of Health and Illness*. Example search terms included: medically unexplained symptoms, chronic fatigue syndrome, fibromyalgia, caregiver, family, significant other, impact, experience, and coping. Both conceptual and empirical studies were also considered.

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[13] An example of this included the use of the truncation technique where an asterisk is placed at the end of a term to search for all terms that begin with that word; for instance non-epileptic* will find all terms that begin with this e.g non-epileptic attack disorder, non-epileptic seizures, non-epileptic seizure disorder

10.2 Appendix B: The University of Hertfordshire Original Ethics Approval

SCHOOL OF PSYCHOLOGY ETHICS COMMITTEE APPROVAL

Student Investigator: Rebecca Davies

Title of project: Living with non-epileptic seizures: The perspective of family members

Supervisor: Nick Wood

Registration Protocol Number: PSY/04/10/RD

The approval for the above research project was granted on 29 April 2010 by the Psychology Ethics Committee under delegated authority from the Ethics Committee of the University of Hertfordshire.

Signed: _Kvavilaш_ (signature)   **Date**: 29 April 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: …………………

10.3 Appendix C: Email from NHS National Research Ethics Service (NRES)

From: NRES Queries Line [mailto:queries@nres.npsa.nhs.uk]
Sent: 18 March 2010 12:10
To: Becky Davies
Subject: 02 RE: 01 RE: Research query: Is NHS ethics approval required?

Your query was reviewed by our Queries Line Advisers.
Our leaflet "Defining Research", which explains how we differentiate research from other activities, is published at:

http://www.nres.npsa.nhs.uk/rec-community/guidance/#researchoraudit

Based on the information you provided, our advice is that the project is not considered to be research according to this guidance.

If recruits are not in the study through NHS routes, then NHS REC review is not needed.

If you are undertaking the project within the NHS, you should check with the relevant NHS care organisation(s) what other review arrangements or sources of advice apply to projects of this type. Guidance may be available from the clinical governance office.

Although ethical review by a NHS REC is not necessary in this case, all types of study involving human participants should be conducted in accordance with basic ethical principles such as informed consent and respect for the confidentiality of participants. When processing identifiable data there are also legal requirements under the Data Protection Act 2000. When undertaking an audit or service/therapy evaluation, the investigator and his/her team are responsible for considering the ethics of their project with advice from within their organisation. University projects may require approval by the university ethics committee.

This response should not be interpreted as giving a form of ethical approval or any endorsement of the project, but it may be provided to a journal or other body as evidence that ethical approval is not required under NHS research governance arrangements.

However, if you, your sponsor/funder or any NHS organisation feel that the project should be managed as research and/or that ethical review by a NHS REC is essential, please write setting out your reasons and we will be pleased to consider further.

Where NHS organisations have clarified that a project is not to be managed as research, the Research Governance Framework states that it should not be presented as research within the NHS.

Regards
****
The NRES Queries Line is an email based service that provides advice from NRES senior management including operations managers based in our regional offices throughout England. Providing your query in an email helps us to quickly direct your enquiry to the most appropriate member of our team who can provide you with accurate written response. It also enables us to monitor the quality and timeliness of the advice given by NRES to ensure we can give you the best service possible as well as use queries to continue to improve and to develop our processes.

**
This reply may have been sourced in consultation with other members of the NRES team.

10.4 Appendix D: Approval from NEAD Trust

Copy of email response from NEAD Trust on 21/04/2010 (replied with relevant documentation on 22/04/10)

Hi Becky,

As you may know the Trustees have discussed and approved your proposal when you first contacted us, so all we need to proceed are copies of the following…

1). Written ethical approval from your governing body.

2). A copy of the research instrument such as a questionnaire or Survey etc.

3). Written guarantee that information given will adhere to the Data Protection Act.

Once we have received these a link to your website / research instrument will be posted on our information page and a message will be posted on our members forum inviting them to take part.

If you should have any further questions or queries or if there is anything else we can help you with please don't hesitate to contact us.

 Kind Regards

NEAD Trust

SCHOOL OF PSYCHOLOGY ETHICS APPLICATION FORM - 3
For minor modifications to an existing protocol approval

Status: Doctorate in Clinical Psychology

Course code (if student): 08190859

Title of project: Living with non-epileptic seizures: the perspectives of significant others

Name of researcher(s): Rebecca Davies (student)

Contact Tel. no: *(contact details have been removed to preserve confidentiality)*
Contact Email: *(contact details have been removed to preserve confidentiality)*

Name of supervisor: Dr Nick Wood (DClinPsy research tutor)

Start Date of Study: April 2010

End Date of Study: July 2011

Details of modification:

After attending a recent conference relating to my research topic, I recognised that I needed to make some minor amendments to my sample criteria. I will outline the changes below:

- Instead of just recruiting family members of people with non-epileptic seizures (NES), as stated in my original proposal, I am hoping to broaden my criteria to enable me to recruit other individuals of significance who support and care for individuals with NES (e.g. partners, spouses, close friends), as well as family members. I have changed the wording on my participant information sheet to:

  This study will include adult carers/significant others (e.g. partner, spouse, family member or close friend) who support individuals (18 years of age and above) with non-epileptic seizures.

- Following discussion with a consultant neurologist who specialises in NES, we recognised that my previous inclusion criteria that indicated that people needed to have a definitive diagnosis of NES was likely to be too limiting, particularly since it is very hard to be 100% confident about the diagnosis. As such, in consultation with the consultant neurologist, I am hoping to broaden my criteria to take this into account and have changed the wording on my participant information sheet to:

  These seizures will be understood as non-epileptic, following the exclusion of a diagnosis of epilepsy and other possible neurological causes as a basis for the seizures, by a consultant neurologist or other appropriate medical professional over recent years.

- As a result of these changes, I will be required to change the title of my project to: *Living with non-epileptic seizures: the perspectives of significant others* and make amendments to

my participant information sheet. I have enclosed my updated consent form, participant information sheet, topic guide and debriefing sheet to the appendices of this document. I have also attached some additional information including the website advert and a transcription agreement that I may use if required and if participants grant their consent for a transcription service to be used.

Does the modification present additional hazards to the participant/investigator? *(delete an inappropriate option category)*	NO
If yes, please provide a clear but concise statement of the ethical considerations raised by the project and how you intend to deal with them.	

This form should be submitted (via your Supervisor for MSc/BSc students) to the Psychology Ethics Committee, psyethics@herts.ac.uk where it will be reviewed before being approved by chair's action.

PLEASE ATTACH COPY OF ORIGINAL PROTOCOL APPLICATION

Appendices:
1. Copy of original protocol application
2. Advert for website
3. Updated participant information sheet
4. Updated consent form
5. Updated topic guide for interviews
6. Updated debrief and feedback sheet
7. Transcription agreement form

Name REBECCA DAVIES………….………..…..Date 22/05/10
(Student Researcher)

Name: NICK WOOD   Date 22/05/10
(Research supervisor)

APPROVAL OF PROTOCOL APPLICATION FOR MODIFICATION

We support the approval of modification of the above protocol	X
We **do not** support the modification of the above protocol for the following reasons:	

Signature _Kravilau_   **Date 10 June, 2010**

Chair of Ethics Committee

Ethics LK/CH/2006
Created: 19/09/06

INFORMATION SHEET FOR PARTICIPANTS

Research Title: Living with non-epileptic seizures: The perspectives of family and friends

Introduction
You are invited to take part in a research study exploring the views of family and friends (i.e partners, spouses, family members or close friends) who support adults with non-epileptic seizures (NES).

This information sheet aims to explain how and why the research is being carried out. Before you decide whether you would like to give consent to take part, please take the time to read it through.

The researchers
The study is being carried out by myself (Rebecca Davies), Trainee Clinical Psychologist, as part of a Doctoral qualification in Clinical Psychology at The University of Hertfordshire. The study is supervised by Dr Nick Wood, Research Tutor and Chartered Clinical Psychologist.

What is the purpose of the study?
This research aims to explore how family and friends of people who have NES understand, make sense of and experience the condition. Non-epileptic attack disorder remains a relatively unknown and poorly understood condition and very little is known about the experiences and views of family and friends who support people with NES. It is hoped that this pioneering piece of research will benefit other people in similar situations, in addition to clinical psychologists and other health professionals. It is hoped that with increased understanding, professionals will be able to better tailor services to meet the needs of people who support individuals with NES.

What is involved?
You will be invited to participate in an interview in a location which is convenient for you. The interview will last for approximately one hour; however, the length of the interview will depend on how much information you wish to share. The interviews will be tape-recorded so that I can get an accurate account of your experience. When I have studied your story, the tape will be destroyed and no-one will know it was your story. Every participant will be asked similar questions, however the aim is to hear about your individual experience. Some of the questions may focus on areas such as:
- your understanding of the diagnosis of NES
- ways in which the positive or challenging aspects of the diagnosis may have impacted on your life and how this may have changed over time
- your beliefs and expectations about how the condition should be managed
- ways in which you have coped with the diagnosis
- your views about the support you have received from health professionals and services

Who is eligible to take part?
This study will include family and friends of adults with non-epileptic seizures. These seizures will be understood as non-epileptic, following the exclusion of a diagnosis of epilepsy and other possible neurological causes as a basis for the seizures, by a consultant neurologist or other appropriate medical professional over recent years. The individual with NES will not have an additional diagnosis of epilepsy. Participants will be 18 years or above.

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[1] Please note this is a copy of the most recent information sheet that followed the modifications that were approved for my selection criteria

Do I have to take part?

No. If you do not want to take part, or you change your mind *at any time* during your participation in this study, you do not need to give a reason. Participation is entirely voluntary and you can withdraw at any time.

What are the benefits of taking part?

This research will give you an opportunity to speak openly, talk about and explore your experiences. From many years of clinical experience and research we know that talking about experiences in our lives can be therapeutic and beneficial. It is possible that you may not experience any direct benefits as a result of taking part in this research. However, it is hoped that this research will provide health professionals and other people facing similar experiences, with a deeper understanding into NES.

What are the potential difficulties that taking part may cause?

I am aware from my clinical experience that talking about our experiences may cause some discomfort and distress. If this does occur you can take a break, and you will not be required to answer any questions that make you uncomfortable. You can stop the interview and withdraw at anytime, for any reason. You will be given a number of contact details following the study, should you feel that you require further support.

Will taking part be confidential?

Yes, your participation is strictly confidential. If you agree to take part in the study, your personal information will be stored safely and will only be accessible to the researchers. The transcripts of recordings will be anonymised and stored safely, in a separate location from your personal information. This information will be kept for up to five years after the research is submitted for examination (until approximately June 2016) and will be stored securely according to the University of Hertfordshire's 'Good Practice in Research' guidelines.

The only circumstance under which confidentiality would be broken is if you disclose information that leads me to have serious concerns about your safety or that of others. In this instance, these concerns would first be discussed with you and the research supervisors in order to establish how best to support you.

What will happen to the results of this research study?

The results will be reported in a thesis for the purpose of gaining a doctorate in Clinical Psychology. All identifiable information will be anonymised in the write up of the study. It is hoped that this study will also be written up and published in a psychological journal.

Who has reviewed this study?

This study was reviewed by the University of Hertfordshire Research Ethics Committee and was given ethical approval on the 29th April 2010.

What if I have questions or concerns?

If you have any concerns or further questions about the research, please feel free to contact me.

What do I have to do if I want to take part?

If you decide that you would like to take part in the research, please contact me using the details below and we will arrange a suitable time and place to meet for an interview. I will also give you a consent form to sign to bring along to your interview.

Thank you for taking time to read this.

Contact details: *(contact details have been removed to preserve confidentiality)*

PARTICIPANT CONSENT FORM

Title of Project: Living with non-epileptic seizures: The perspectives of family and friends

Researcher: Rebecca Davies, Trainee Clinical Psychologist

	INITIAL
1. I confirm that I have received a copy of the information sheet in relation to the above study. I have read and understood it and have had an opportunity to discuss it.	
2. I understand that I have the right to change my mind about taking part in the study and can withdraw at any time, without giving any reason.	
3. I give permission to be interviewed by Rebecca Davies for the purposes of this study and consent to the tape recording of my interview.	
4. I understand that my information and tape recording will be stored securely.	
5. I understand that the information I provide will be anonymised for the purposes of this study and that anonymised sections of the data will be looked at by authorised persons from the University of Hertfordshire in order to assess the quality of this doctoral research project. All will have a duty of confidentiality to you as a research participant.	
6. I agree that anonymised quotes from my interview may be used in any publications. I understand that although efforts will be made to maintain anonymity, the use of direct quotations and the individual nature of the analysis means there is a possibility that those close to me might be able to identify me.	

7. I understand that a professional transcription service may be used to transcribe my interview. In this instance, the recording will be given an identifying code (e.g. Interview A) to maintain your anonymity. Furthermore, the transcription service will have signed a confidentiality agreement.

8. I agree to take part in the above study.

Name of Participant: --

Signature of Participant: --

Date: --

Name of Researcher: --

Signature of Researcher: --

Date: --

DEBRIEFING INFORMATION SHEET

Thank you very much for making this study possible.

This study aimed to explore the experiences of family and friends who support and care for an individual with non-epileptic seizures. I was interested in:

- How you understood and made sense of the diagnosis of NES and how this may have changed over time

- How you perceived the impact of the diagnosis on your life, your relationship with the individual with NES, and how this may have changed over time

- What you have found most difficult about the diagnosis and how you have coped with it

- What expectations you hold about the future

- What you found was helpful or unhelpful about any support that you have received and what support you feel you could still benefit from

The current academic literature in this field is almost non-existent, however, some research has been carried out with families and significant others of people who experience different conditions. From this research, it seems that such conditions can also impact on family and friends. It was hoped that this exploratory research would help us to gain an insight into your experiences and provide a foundation on which discussion regarding psychological theory and appropriate interventions can begin.

In the event that participation in the research has raised any issues or concerns for you, please do not hesitate to contact me, or my supervisor, using the details below. Both will be available for contact for a period of six months after your interview occurred.

Miss Rebecca Davies	Supervisor: Dr Nick Wood
Trainee Clinical Psychologist	Clinical Psychologist
University of Hertfordshire	University of Hertfordshire

(contact details have been removed to preserve confidentiality)

<u>SOURCES OF COMFORT AND HELP</u>

Talking about your experiences may have left you feeling low or upset, this is quite normal and often passes after a few days. However, if these feelings persist there are local sources of support and comfort which may already be familiar to you.

1. The most immediate sources of comfort and help are likely to be *your own family and friends*.

2. *Your GP* may be able to refer you to more specialised local support services such as counsellors if you feel this may be of benefit.

The following national organisations offer support:

3. *The Samaritans*
     Telephone: 08457 909090
     Web address: www.samaritans.org

The Samaritans is a helpline which is open 24 hours a day for anyone in need. It is staffed by trained volunteers who will listen sympathetically.

4. *Carers UK*

     Telephone: 0808 808 7777

     Email address: adviceline-@-carersuk.org

     Web address: http://www.carersuk.org/Home

CarersUK provides high quality advice and information to carers and the professionals who support carers. The advice line is staffed by experts who have many years of experience of dealing with the problems carers face. The advice line is open on Wednesday and Thursday 10am-12pm and 2pm-4pm. You can also email them on the address above.

University of Hertfordshire

Hatfield

Hertfordshire

AL10 9AB

23/04/10

To whom it may concern,

My name is Rebecca Davies. I am undertaking my Doctoral training in Clinical Psychology at The University of Hertfordshire. As part of my qualification, I will be undertaking a research project. I am writing this letter to provide you with an overview of this research project, in the hope that you might be interested in participating.

The title of my research project is: **Living with non-epileptic seizures: the perspective of family members**

This research is interested in finding out about how family members of people with non-epileptic seizures understand, make sense of and experience the condition. At present, very little is known about the experiences of family members living with and caring for a member of their family who has a diagnosis of non-epileptic attack disorder. Thus, participants would have the opportunity to be one of very few people to have their voices and experiences heard.

Who can participate?

I am looking for adult family members or partners who are currently living with or caring for an individual who has a diagnosis of non-epileptic attack disorder.

Why is this research important?

This is an important pioneering piece of research. I am hoping that this research will increase our existing understanding about non-epileptic seizures and offer insights into the experiences of this condition from a family perspective. It is hoped that this information will benefit other families in similar situations, in

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[1] Please note that this refers to inclusion criteria prior to the modifications that were approved

addition to psychologists and other health professionals, and indicate what families would find helpful from services.

What would participation involve?

Participation would involve a recorded interview which would last approximately one hour. This would take place at a time and place that best suits you. The interview would be confidential. During this time, we would talk about your understanding of the diagnosis of non-epileptic attack disorder and your experiences, both the positives and possible challenges of living with and caring for an individual who experiences non-epileptic seizures. We would also talk about the things that you have found helpful or unhelpful and your views about any support that you may have received from health professionals and services.

It is hoped that interviews will give participants an opportunity to speak openly, talk about and explore their experiences. I am aware that for some this conversation may be sensitive, and wish to clarify that you would not have to answer any questions you did not want to.

If you are interested in finding out more, or would like to take part, then I would be delighted to hear from you. I can then provide you with further details before you decide whether you would like to participate in this research project.

My contact details are:
(contact details have been removed to preserve confidentiality)

Yours faithfully,

Rebecca Davies   Supervised by Dr Nick Wood

Trainee Clinical Psychologist   Research Tutor & Chartered Clinical Psychologist

10.10 Appendix J: Advert for NEAD Trust Online Forum

An invitation to participate in some research

Do you support someone who experiences non-epileptic seizures? Would you be interested in taking part in some research?

My name is Rebecca Davies and I am currently completing my Doctoral training in Clinical Psychology at The University of Hertfordshire.

I am carrying out some research to explore the views of family and friends (i.e. partners, spouses, family members or close friends) of people who have non-epileptic seizures. In particular, I am interested in finding out about how family and friends of people with non-epileptic seizures understand, make sense of and experience the condition. As non-epileptic attack disorder (NEAD) remains a relatively unknown and poorly understood condition, I hope that this pioneering piece of research will increase the existing understanding and offer new insights by learning about the condition from those supporting people with NEAD. It is hoped that this information will benefit others in similar situations, in addition to psychologists and other health professionals.

I am inviting family and friends of adults who experience non-epileptic seizures to participate in my study. Participation would involve a confidential interview which would last approximately one hour. This would take place at a time and place that best suits you. During this interview, we would talk about your understanding of the diagnosis of NEAD and your experiences of supporting an individual with NEAD.

I would be delighted to hear from you. If you are interested in finding out more about this study or would like to take part, please contact me on *(contact details have been removed to preserve confidentiality)* and I will provide you with further details.

I look forward to hearing from you.

Rebecca Davies

10.11 Appendix K: Advert for NEAD Trust Facebook Page

AN INVITATION TO TAKE PART IN A PIONEERING RESEARCH STUDY

Are you a family or friend of someone who experiences non-epileptic seizures? Are you interested in taking part in a pioneering research study to help increase the existing knowledge about NEAD?

My name is Becky Davies and I am inviting family and friends of adults who experience non-epileptic seizures to take part in an hour-long confidential interview to talk about how they understand, make sense of and experience the condition.

I would be delighted to hear from you. If you are interested in finding out more about the study, please contact me on *(contact details have been removed to preserve confidentiality)* before July 14th 2010 or send me a facebook message and I will provide you with further details.

I look forward to hearing from you.

10.12 <u>Appendix L: Follow-up email to potential participants[15]</u>

Dear,

Further to your recent email, I continue to seek family members or friends of adults with non-epileptic attack disorder to volunteer for my research study. If you are a family member or friend of someone who experiences non-epileptic seizures, I am writing to enquire whether you might be interested in taking part in my research. Alternatively, if you know of somebody who may be interested in volunteering, please could you ask them to contact me.

My project studies how family members and friends of adults with non-epileptic attack disorder understand, make sense of and experience the condition. As such, I am inviting adult family members or friends who are currently caring for or supporting an adult who has a diagnosis of non-epileptic attack disorder to volunteer for my study. Participation would involve a confidential interview which would last approximately one hour. This would take place at a time and place of your convenience.

At present, very little is known about the experiences of family members and friends who care for or support individuals who have a diagnosis of non-epileptic attack disorder. Taking part in this study offers participants the opportunity to have their voices and experiences heard.

If you are interested in taking part, then I would be delighted to hear from you as soon as possible, and before Friday 6th August 2010.

Please do not hesitate to contact me if you have any questions.

Yours sincerely,

Rebecca Davies

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[15] This email was sent to individuals who, further to the advertisement of the NEAD Trust website, had requested an Information Sheet but had not been in touch again. It was sent approximately 2 weeks after their original email

10.13 Appendix M: Follow- up advert for NEAD Trust Facebook Page

AN INVITATION TO TAKE PART IN A PIONEERING RESEARCH STUDY

Further to my last post, I continue to seek individuals who are interested in participating in my research. I am inviting family and friends of adults who experience non-epileptic seizures to take part in an hour-long confidential interview to talk about how they understand, make sense of and experience the condition.

If you are interested in finding out more about the study, I would be delighted to hear from you as soon as possible, and before Friday 6th August 2010. Please contact me on *(contact details have been removed to preserve confidentiality)* and I will provide you with further details.

I look forward to hearing from you.

10.14 Appendix N: Topic Guide for interviews

Before I ask you about your story, I wondered if I can ask how you came to volunteer to take part and what your hopes may be.

Introduction question:

As you know, as part of this study, I am interested in hearing about the experiences of family members and friends who support individuals with NEAD

I wondered if you could begin by telling me in your own words something about your experiences of supporting * with NEAD, beginning at a place where you feel is most appropriate to start.

If initial prompt needed:

I was wondering if you could tell me about your experiences as if it were a story with a beginning, middle and how things will look in the future … perhaps starting with what things were like before the diagnosis, to what life was like afterwards and now and so on…

General prompts to use throughout:

- Could you tell me a little bit more about that?
- Can you give me a specific example?
- What happened next?
- Can you explain what you mean a little more?
- WHAT IS IT LIKE FOR YOU?
- What was the experience like for you?
- How have things changed over time?
- I was interested in hear about (reference to the topic) and wondered if you can tell me a bit more about that

Understanding	1. **Can you tell me a bit about what your understanding of NEAD was at that time?**
	- Before diagnosis- can you tell me a bit about what your understanding of *'s seizures was at that time, before *'s diagnosis of NEAD?
	- At time of diagnosis
	- Early stages of diagnosis
	- Now - do you think your understanding has changed over time?
Response to Diagnosis	2. **Thinking back, can you tell me a bit about how you responded to the situation at that time?**
	- Before diagnosis
	- At time of diagnosis
	- Early stages
	- Now
Impact	3. **Can you tell me a bit about what it was like for you at that time and what effect supporting someone with NEAD had on your life at that time?**
	- Before diagnosis- can you tell me about was this period of time was like for you before *'s diagnosis?
	- At time of diagnosis- Can you tell me about what it was like to learn about the diagnosis and what it felt like for you?
	- Early stages
	- Now
Coping	4. **Can you tell me a bit more about the kind of challenges that arose for you as a carer for someone with NEAD at that time and how you feel you managed these?**
	- Before diagnosis
	- At time of diagnosis
	- Early stages
	- Now

Services	**5. Can you tell me a bit about your experience of the type of support from services and health professionals that you and * received at that time?** - Before diagnosis - At time of diagnosis - Early stages - Now
Future	**6. Can you tell me about how you see being a carer as you look into the future** - Can you tell me a bit about the kinds of challenges you anticipate may arise for you in the future and how you feel you may manage them? - Can you tell me about your thoughts about the kind of treatment you would like * to have in the future and what kind of support you think you'll need in the future?
Summary	7. In summary, I wonder if you can share with me some final thoughts about what it means for you to be a carer/supporter for someone with NEAD? 8. What advice would you give to people who are in a similar situation to you and why? 9. What advice do you think health services need to know about NEAD from your perspective in order to provide effective services?

Home visit guidelines

HOME VISITING GUIDELINES

- Prior to visiting a participant's home, the participant's full address will be made accessible to the research supervisors.
- Further to this, the researcher will have arranged to contact the research supervisors on leaving the premises.
- In the event that contact is not made, the research supervisors will seek to contact the researcher via mobile phone.
- If these further efforts at making contacting contact are unsuccessful, safety procedures will be followed and support from the local authorities may be sought.

Transcription Agreement

Doctorate in Clinical Psychology

University of Hertfordshire

Transcription confidentiality/ non-disclosure agreement

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

Rebecca Davies ('the discloser')

And

Hire A Typist 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:……………………………….

10.17 Appendix Q: Evidence of Analysis

Audit Trail of process of analysis for James' narrative

<u>Stage 1</u>

Whilst listening to the interview and reading the transcript, I read my post interview reflections. An excerpt of my notes is included below:

Post interview reflection- What were the stories most strongly heard?

- NEAD appears life changing for him – practically, emotionally and in his relationship with his partner

- Onset was confusing and frustrating but diagnosis depicted as a turning point – justified the seizures and his role - and offered opportunity to reflect and move forward- at time of interview, sense that James and his partner were starting to move forward, with the diagnosis being a positive turning point in helping them to consider 'what are we going to do if these seizures continue' – may have heard a different story with more struggles a few months earlier

- Very passionate about his caring identity- spoke emotionally about previous experiences of caring and of his commitment to 'make the best quality of life' for his partner – seemed to be a thread running through narrative and often in context of talking about struggles – as though wanted to illustrate to the reader that he can cope - was struck by his seemingly self-less attitude towards his role. However, at the same time he alluded to feelings of regret about the some of the things he had had to sacrifice to care for his partner (in particular his work).

- Caring role not recognised by members of society- e.g. DLA and family members, who think 'we're trying it on'

- Ambivalent reaction about future- spoke of both feelings of optimism and pessimism about the possibility that things won't change

- Keen to share his experiences and stories to help other 'carers'

<u>Stage 2: Reading for Content – the 'told'</u>

Drawing on Lieblich et al's (1998) stages and after several readings of the text, I made a note of my 'initial impressions' of the key stories/content:

- Story of diagnosis – this was big point– process leading up to it was frightening, frustrating, confusing (story of onset)– diagnosis enabled them to feel justified that there was a 'problem' and to move forward – encouraged a positive and proactive response – "so what are we going to do about it" – but some conflicting feelings too – where next?

- Diagnosis led to some understandings developing but also faced with ongoing struggles to make sense of 'confusion' (stories of understanding)

- "It's life- changing" – it's 24-7; can't plan to do things he likes; loss of sleep; frustrating; shattered (stories of changes)

- Impact on relationship – takes time away from each other (stories of changes)

- Frustration about lack of understanding of others and lack of interest showed by others – sense of doubt by other people, including family members about the validity of the condition (stories of encounters with others)

Using coloured markers, I subsequently tracked each (thematic) story throughout the text i.e. stories of onset; stories of diagnosis; stories of changes and considered how he talked about these stories over time. I subsequently moved together stories with similar themes under three main 'thematic storylines'. For the purposes of clarity, I have presented these three thematic storylines and a selection of the corresponding sub-stories that James spoke about in the table below:

The development of understandings about NEAD		
Stories about onset	287:222[1]	• "I didn't know what was causing it and it was quite frightening because she would just literally [pause]…she could be standing…and she'd just go [click of fingers] onto the floor with no warning"
	287:226	• "epilepsy didn't cross my mind. I was more concerned that it was either something cardiovascular wise or, or, or even something in, in, in the brain, in the head. Um, so it was extremely frightening"
	287:238	• "it's epilepsy, and we said, but no, you know, the other doctor said no, it's not epilepsy, you know, and, and so on. So we were confused"
	289:286	• "I didn't understand it… but my priority was just to be there"
Stories about diagnosis	299:584	• "having a diagnosis was, was, was, the big point for us"
	299:589	• "being justified in, in saying, you know, there is something wrong here. Just knowing that, that somebody says yes, this is what the problem is was, was a relief for both of us:
	299:595	• "For me, I think that was the point right, okay, we know what the diagnosis is….it's time to start trying to move forward with the illness"
	300:604	• "We've got a diagnosis so what are we gonna do about it?"
	300:609	• "we need to change the way we do things and we need to look at how we can adapt to, to dealing with life"
Stories about understandings	290:320	• "You know, where does that come from? What, what's causing that? Where is she in her mind to be coming out with that sort of stuff? Um, I mean it is, it's frightening and it still is"
	291:348	• "some of the stuff is absolute rubbish, gobbledegook. She's got a fixation on mangos which do not play a part in her life and I've never known her eat one, but mangos quite often comes up and I don't' know why. Um, you know, i..it's all very confusing um, and quite concerning"

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[1] Page number: line number

	291:356	• "Oh definitely. Definitely. Um, absolutely"
	293:405	• "I understand the, the, the bits to a point"
	293:395	• "I just deal with it differently now. Um, so I, I consider that as part of understand in…certainly in terms of the way of dealing with it"
	295:471	• "I have a better understanding of a better way to deal with it for her…..it's less stressful"
	308:852	• "But at least now I know what it is and I know she won't come to any harm, but it doesn't stop me worrying"
	310:899	• "That would also partly explain the confusion"
	310:902	• "When he said, um, this could be caused by some past trauma then I definitely latched onto that"
Stories about future	288:266	• "we're we're 16 months down the line and we, we now know what it is but we still don't know what's going to, er ease it, if anything"
	311:932	• [psychotherapy] "I think that may help if they can get through to her"
	313:1008	• "at this moment in time, um, I don't see any of that changing…..or until we see when the psychotherapy comes up whether that makes any different or not"
	320:1202	• "I've got quite a, a depressive look on, on the future, um, um…until this, this psychotherapy comes up"
	320:1219	• "I signed up for the long haul and that, that…you know, if that's how it is it's how it is, but I mean I hope to god it isn't for both our sakes"
Living with NEAD and managing lifestyle changes		
Managing changing roles	282:69	• "I don't have a problem that she's got an illness and we're…you know, we're together and I don't mind caring for her"
	282:77	• "I mean, she's my partner…"
	292:391	• "I've sat down and cried at times"
	293:398	• "It's horrible because I can't do anything to help her"
	301:636	• "tried to, um, make the best quality of life for him that I could um… my, my nature is to work with people who, who

		have different types of illness"
	302:668	• "I'm always looking at trying to maximize life's opportunities within people's boundaries and I see no different with doing that with my partner as I would with people that I work with either voluntary or paid"
	303:695	• "But it's not easy and it, and it is a struggle and sometimes I'm really depressed because I hate seeing her like that, but, you know, all, all carers go through that, er, at some point"
	305:753	• "Well I just feel that I want to be involved in raising awareness of it by coming to this"
	305:762	• "because I think it's important. I think it's important for people to understand what, what sufferers go through, people who have it, um, and what the carers go through cos it is life changing. You know, it changes her life and it changes my life"
	318:1157	• I've very proud of looking after her and being her carer and I haven't got a problem doing it, but I also feel that I'm not fulfilling my worth by not going out and doing what I was doing as well. So it's a bit of a hard balance to make"
	321:1256	• "I know it sounds awful but, you know, it really is 24/7 and there are times when I just think you know, as much as I love her and everything I would just like to just go somewhere for the day………er, and having done respite care"
	326:1399	• "you have to think about the thousands and thousands of carers of people with, with a variety of illnesses….you know, the carer's role is, is a hard one but there are lots and lots of people doing it"
Managing changing relationships	281:47	• "Right. I think key word for me is frustration. Um, it's, it's very frustrating to see Clare go through this. It obviously upsets her….I just find that so frustrating because I can't get her out of that confusion"
	282:78	• "It actually takes away a lot of our time together"
	283:114	• "And I said but you've had a fit today….Oh I don't remember. Can't we go out? But it's ten o'clock"
	284:131	• "I'm always conscious where is she….which is like 24/7"
	284:138	• "I thought that's funny, and she was on the floor [laughs]. I didn't even know she'd gone….You know, and, and that's, that's how it is"

	297:540	• "I know it sounds selfish, but all carers need to have a break and refresh as well"
	306:801	• "I mean today I'm here with you. Now, Clare is across the road in the bingo hall but she's got somebody with her……it has to take that sort of arrangement"
Managing changing working lives	283:91	• "there are things now that I used to do that I can't do. Um, I do a lot of voluntary work. I work with people with mental health problems and learning disabilities, um, but I can't commit to that"
	283:96	• "because I can't go and leave Clare"
	291:358	• "I work with people with mental health problems"
	306:787	• "I cannot plan to do anything"
	306:792	• "I'm actually able to go on the organist rota and the reading rota and not let them down"
	307:828	• "I can't just say okay, well you stay here and I'll pop to Morrisons for two hours. I can't do it"
	308:848	• [situation where clare had collapses in back yard] "you know, I was, I was at the point of breaking my own front door down to get in, you know, because I'm worried"
	318:1151	• "for me, personally, er, was disappointing because I enjoy my work"
	322:1286	• "send her in a cab, not a bus. So it does, it does have a, you know, an impact financially as well that we need to do things slightly differently and more carefully"
Encountering others and NEAD		
Encountering family, friends and the general public		
Misunderstandings of others	280:12	• "you tell people what it is and they've never heard of it"
	285:179	• "we know but they don't. It's quite difficult sometimes"
	286:182	• "Basically [sigh] that it's like epilepsy but it's not. That's …it's got to be the easiest way to explain it"
	292:378	• "I…try and explain to people that I need to be with her all the time….they're not having it. DLA won't have it. They're

		not interested. They, they've never heard of NEAD and don't accept that I should be 24/7"
	296:499	• "we're not gonna tell strangers that she's waiting for psychotherapy"
	303:710	• "nobody says oh yeah, you know, my, my uncle had that. Nobody ever [laughs] sort of says oh yes, we know what that is"
Negative reactions of others	284:145	• "Horrible [in reference to when Clare had a seizure at bingo]. Because then of course when I get her up everybody's oh that woman's passed out, ner, ner, ner"
	285:157	• "voice came down the carriage, does this woman belong to anybody"
	285:161	• "People were trying to get on and she was laying on the floor. Just like that. It's, it's horrible. It really is horrible"
	285:168	• "And then when you sort of get her up….people think you're actually being cruel, that you, you know, that you should be doing more"
	286:193	• "the foaming at the mouth…when that happens in public, you know, people look"
	286:210	• "my, my priority is to make sure Clare's alright and what other people think is just, you know…by the way [laughs]. Basically"
	292:384	• "her parents seem to think that we're just trying it on……and I, I also feel that sometimes they don't realise what I go through looking after her, how upsetting it can be"
	297:519	• "they have no idea what I go through on a daily basis and I'm angry because I care for their daughter and look after her and they seem to think that we're, you know, not doing anything…which is not the case"
	314:1035	• "they have no idea that, that, you know, sometimes I'm up 48 hours on the trot when she doesn't sleep…you know, it is a full time responsibility"
Lack of support	298:568	• "because it does isolate you to a certain extent"
	314:1030	• [in context of support] "say the family, they don't understand it and they don't seem to want to understand it"
Establishing connections	280:9	• "I…we, we….we found a, a, support group in….which we haven't attended yet but we intend to"

	297:533	• "I've got people now who are, er, aware of her situation and aware of what to do if she does have an attack"
	299:549	• "trying to arrange that has been difficult but I'm getting there slowly"
	299:556	• "where they've shown an interest and been willing to help"
	305:750	• [story about talking to another support worker recently about NEAD] "and that's the nearest I've got to anybody even showing the slightest interest or having any idea about what this is about"
Encountering the medical profession		
Lack of support	295:480	• "if you've got epilepsy then, then you've got a list of things that, you know, okay, if, if they're having this sort of seizure you do this and this and, you know, there is nothing to refer to"
	305:768	• "as long as we've got information and support then, then we'll cope with that, but we felt we didn't have that up until we got a diagnosis"
	311:955	• "the support that we've had, ie. Clare and I, well, I would say that's practically zero"
	316:1111	• "if you get a diagnosis for cancer or, you know, Alzheimers' or anything else you get information. You get a booklet or you, you get put in touch with support groups or whatever. But it just felt well why is there nothing for this"
Establishing connections	312:967	• "the only person I would, would way has been supportive is her GP, um, who's taken an interest throughout"

Stage 3: Reading for Performance – the 'telling'

At the same time as reading the text for content, I considered the questions as proposed by Riessman (2003) to consider the relational and performative aspects of the storytelling.

In what kind of stories does James place himself?

- As a caring partner who is frustrated by the life-changing impact that NEAD has created in their lives – sense that this role is unquestioned – "she think she's a burden….I don't mind caring for her…I mean she's my partner"

- As someone who has cared before and feels comfortable and at 'ease' in adopting this role again – (caring as a form of 'biographical continuity')

- As a martyr? / Self-less and 'protective' partner (the only person willing to understand and support her and make sacrifices in his life - "I'm prepared to do anything for her"; "I signed up for the long haul"; "I didn't understand it but my priority was just to be there")

- As a 'coper' and a fighter- sense of movement over time, away from disruption following the onset of Clare's seizures (even if this movement is tentative and fluctuating at times)

- As a carer, who wants to advice others through the struggles – "I want to be involved in raising awareness of it by coming to this…I think it's important for people to understand what, what sufferers go through and what carers go through 'cos it is life changing"

Why was the illness narrative developed that way and told in that order?

- Opens narrative by talking about 'we' to refer to a joint decision that Clare and himself are making in relation to her condition and continues this throughout narrative ("we found a support group"; we've got a diagnosis so what are we gonna do about it?")– aligning himself alongside and in close proximity to Clare- appears to reflect a shared journey of struggles

- Also opens narrative by telling of his frustrations – in particular, the impact on his partner and their relationship – "it's very frustrating to see Clare go through this" (places Clare at the centre of the story- presents himself as someone who is empathetic towards her experiences) – but also the impact on his difficulties to 'fulfil' his role – "I can't get her out of that confusion" (maybe that is different to previous experiences of caring?)

- Tone reveals the struggles, in particular anger and frustration towards people who misunderstand/ are negative towards Clare and the condition – defines others as 'they' – thus referring to them as anonymous and threatening towards him and Clare – located at a distance

How does James strategically make preferred 'identity' claims?

- Attempts to portray himself as a relatively strong and capable 'carer' – this is perhaps an important self-narrative for him but may also want to present a relatively 'positive' message to other 'carers' in his audience.

- Positions himself as a 'carer' – talks extensively and emotionally about previous roles as a carer – positions himself alongside the experiences of other 'carers' – helps him to feel connected with similar others (which may be particularly important for him due to living in an environment where others judge him and Clare) and less 'unique' in his role?

- Positions his partner as a 'victim' to the condition and consequently himself as the 'rescuer' – as the 'good carer/partner' protecting his partner

- Searches for allies from me and his audience- tells stories to emphasise his struggles – "I was at the point of breaking my own front door down to get in, you know, because I'm worried" - perhaps needs allies to his story due to experiencing others thinking they are putting it on

- Positions self as someone who is experienced in supporting people with learning disabilities and mental health conditions – presents self as being knowledgeable about a range of conditions – perhaps important to 'hang on' to these stories and experiences in the context of so much uncertainty in relation to NEAD?

What other identities are performed or suggested?

- Sacrificed a lot– where has 'partner' identity gone? – appears to struggle to tell some negative stories– often wants to remind audience of his love and commitment towards his partner- "I know it sounds selfish but…." and "as much as I love her"…

- As someone who is vulnerable at times and struggles with the negative reactions of others- "my priority is to Clare…who carers what others think. Basically" – story implied that he may be less immune to their criticism than he wants to present – also that he is "depressed…shattered…pessimistic about future" – but these stories are often brief, perhaps reflecting his reluctance to expand on these stories in more detail to somebody he does not know

- As someone who cannot understand their experiences, in particular Clare's seizures – contrasts this to his portrayal of himself as someone who is knowledgeable about Learning Disabilities and Mental Health

What was the response of the listener/ audience and how did it influence the development of the narratives?

- Mostly made affirming noises that may have persuaded more stories of struggles

- Wondered if as a professional – he wanted to portray to me that he was coping – wants me to look at him and see him as someone fighting, who will overcome it

Stage 4: Reading in context

Whilst reading James' narrative, I considered literature on discourses about informal caregiving and narratives about the 'good carer' (Pickard, 2010) and about male caregiving (Calsanti & King, 2007).

<u>Stage 5: 'Global impression' of James' individual narrative</u>

After the completion of the analysis for individual narratives, I wrote a 'global impression' for each individual that integrated the key aspects emerging from the content and performative analysis.

James individual narrative

James' narrative focused on three key storylines: (1) a developing understanding about NEAD, (2) the life changing nature of NEAD, and (3) encountering the sense making of others about NEAD.

Storyline 1: Developing understandings about NEAD

A sense of fear and confusion was prevalent in James' stories about the onset of his partner's seizures. For example, he described this as an "extremely frightening" time, which was accompanied by early interactions with health professionals who didn't know what was happening and questioned many possible diagnoses, such as heart disease, epilepsy, migraine or "something in the brain". James listed these in quick succession, helping to represent the sense of confusion that they both felt.

He highlighted that Clare's diagnosis of NEAD was a relief for them, in that they were "justified in, in saying, you know, there is something wrong here…this is what the problem is" and a turning point in their thinking towards the condition: "we've got a diagnosis, so what are we gonna do about it?" When asked about his change in understanding over time, James spoke about "definitely" getting a better understanding over time, which he attributed to the clear explanation about NEAD that they received from Clare's Consultant. However, at the same time, he repetitively asked rhetorical questions such as, "where does that come from? What's causing that?" when referring to Clare's seizures and the use of his questioning suggested that, at the time of the interview (perhaps due to the relatively recent diagnosis of his partner's seizures), he was still engaged in a struggle to fully make sense of her experiences. His selection of stories, for example, referring to the "absolute gobbledygook" that Clare verbalizes during her seizures, in addition to the telling about her "fixation of mangoes", which he followed with an aside to the audience that mangoes "do not play a part in her life", appeared to further emphasise his current sense of confusion and fear in relation to the seemingly random and bizarre images during episodes. In talking about the future, James spoke of his hope that psychological therapy may "ease it" but similar to Brian, alluded to his uncertainty about whether it will ultimately "help with the NEAD, I don't know".

Storyline 2: Life changing nature of NEAD

This storyline seemed to link directly to his purpose for taking part in the research:

"I want to be involved in raising awareness of it by coming to this,….I think it's important for people to understand what, what sufferers go through and what carers go through cos it is life changing"

The impact of NEAD on his relationship with Clare appeared a key story, as suggested by the location of this story at the start of his narrative. From the outset, James appeared to place Clare at the centre of his story and presented himself as someone who cared for and was empathetic towards her experiences. He spoke of his frustration (a key emotion that he expressed frequently throughout his story) about the fact that NEAD "takes away a lot of our time together". Through his use of pluralism, which he appeared to very consciously correct in the opening line of his story "I..we we", he painted a picture that they were on a shared journey and offered examples of times when they worked through challenges together, for example by talking about her feelings after a seizure. However, whilst portraying a strong sense of commitment to their relationship, where Clare is always a "priority" for him, he acknowledged that "I'm very proud of looking after her…but …it's a bit of a hard balance to make", suggesting that he was at a point in their journey where he was recognizing the need but finding it a struggle to prioritize himself and his needs.

In relation to other aspects of his life, James spoke of the fact that he "can't commit to" voluntary work or activities that he previously enjoyed and "can't go and leave Clare" as a result of the "full time responsibility" of caring for Clare. It also appeared that his experiences of caring for Clare had been emotional, reflected through his frequent use of emotional language, and particularly at times when he repeated words such as "It's, it's horrible it really is horrible". These negative emotions were often in reference to situations when he was out of the home environment. For example, when describing a recent train journey when Clare had a seizure, there was a sense that his story was like an emotional outpouring, where the pace quickened, and there were many broken or unfinished sentences. He also described the intense worry that could accompany times when he was concerned that Clare may have injured herself as a result of a seizure when she was alone in the home and the sense of this intensity was heightened in the way he drew his listeners into his story, for example, "I was at the point of breaking my own front door down to get in, *you know (italics added for emphasis)*, because I'm worried what, what…what's occurred".

Whilst James acknowledged, towards the latter stage of his story that he had a "depressive outlook on the future" and questioned if anything would ever "ease it", a concern that was emphasized further by his reference to time in his story "we're 16 months down the line…", there was also a sense that James had had time to process the impact that NEAD has had on their lives and was becoming more reflective and hopeful about the future. He described that Clare's diagnosis was a turning point in encouraging a change in attitude and recalled his thoughts at the time, for example "we've got a diagnosis, so what are we gonna do about it?... we need to look at how

we adapt to life". Already, he illustrated how they had taken action to implement some changes in their lives, such as drawing on support offered by other people, which suggested that despite the uncertainty that Clare's condition brought, they had found a sense of agency over aspects of the problem and were able to step away from the seeming absorbing effects that it had thus far had over their lives.

Storyline 3: Encountering the sense making of others and NEAD

James also spoke about his frustrations towards the lack of understanding about NEAD from others and their lack of interest and awareness about the condition. "Other people" appeared to be located at a distance from his and Clare's experiences and there was a sense that "they" were perceived as a homogenous threat to his and Clare's life, all of whom remained nameless throughout his story. When describing interactions with "other people", his tone often appeared bitter and resentful and he portrayed a perception that Clare was often referred to by others in derogatory and inferior ways, for example as "that woman". He also portrayed a strong sense of anger about the judgmental attitudes of public services such as DLA, and family and friends who "poo poo the idea" and are judgmental towards his role in supporting Clare – "[they] seem to think we're just trying it on". It is possible to infer that by reference to the idea of "trying it on", he was referring to a societal attitude and lack of understanding about psychological problems that, whilst may remain present in current society, may have been more dominant in certain family member's generation. It is interesting to consider that he too, given his age, may have come from a generation where 'stigma' was attached to "fits" and 'fits' in public but that he was now in a position where he had to break out of that belief and move forward with his thinking. It was possible that his sense of frustration towards some of their family and friends may be connected to his awareness of their unchanging and rigid attitudes.

Whilst there was a sense that James was only at the start of a journey in managing and making sense of the responses of other people, there was some hope that he and Clare had began to make some connections with people in their local community who wanted to help e.g. the minister of their local church and that he was starting to consider the benefits of turning to others. It is possible that as a male, who had historically spent his time caring for others, this represented a significant step in his journey.

Stage 6: Comparing and contrasting narratives

After completing analyses for each individual narrative, I held narratives side by side and compared them by, for example looking at the different storylines and the movement of plots throughout the narrative (i.e. whether their narrative suggested some movement over time away from disruption or whether it was predominantly still focused on the disruption). I have written a brief extract of the notes I made when comparing two narratives:

	James	Nicola
Sense Making and NEAD	- Narrative depicted onset as being a disruptive experience – frightening, scary, confusing - Diagnosis offered some form of turning point – sense of relief that seizures did not represent something life-threatening – and turning point in thinking. - Spoke of developing some understandings over time, although narrative portrayed that he still had some questions remaining about the nature of his partner's seizures	- Narrated very detailed story about onset of seizures and used many words to describe her daughter's seizures, serving to illustrate the 'lack of a label' for the condition that spanned approx 5 years - In comparison to James' narrative, Nicolas' narrative did not depict much change over time following the diagnosis of NEAD- she spoke of her sense of disbelief in the diagnosis, lack of understanding and of her concern that she may be to blame for the seizures
Living with NEAD and lifestyle changes	- Spoke of a range of changes in his life following the onset of his partner's seizures, including changes to relationship with partner, to his working and social life - Despite the ongoing impact of these changes, James spoke of his priority towards his partner- who appeared to take precedence over the changed nature of his life. In managing the changes, he also appeared to draw on his life-long history of caring and spoke of his hope that he could ensure	- Narrative portrayed the significant changes that occurred in her life, in particular in her relationship with her daughter - Narrative portrayed that these changes were ongoing at the time of the interview and were continuing to have a disruptive impact on her life - Portrayed a sense that the changes disrupted her sense of identity- 'felt emotional and useless as a mother as

	that his partner could have the 'best quality of life, within her abilities' • Some brief and underdeveloped stories about his struggles	unable to make things better' – not what she expected from her and her daughter's life – spoke of struggling to 'let go'
Encountering others and NEAD	• Spoke of his frustrations towards the lack of understanding and critical judgements of others • Portrayed himself as attempting to cope with these by learning ways of managing and distancing himself from his emotions and putting his priorities towards Clare first • However, some stories illustrated the impact that the reactions of others had on his sense of self	• Spoke of her frustrations towards the lack of understanding, critical judgements and lack of support from others • Depicted self as struggling to manage these reactions and spoke of finding it easier not to talk to others about condition due to their misunderstandings – portrayed self as relatively isolated
Overall 'story type'	• Story of 'biographical continuity' was heard most strongly in his narrative, through his unquestioning assumption of his caregiving role towards his partner and a sense that the current caregiving role reinforced his sense of self as a carer • However, this did not prevent stories about the disruptive nature of some aspects of his experience from being heard, albeit briefly	• Story of 'biographical disruption'

10.18 Appendix R: Transcript of Interview

For the purposes of anonymity, the transcript has been removed and is only in the examiner's copy. The transcript was pages 279-326.