

**Seizure clinic encounters:
Third party references and accompanying others.**

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Abstract

There are two different types of seizures, epileptic and psychogenic non-epileptic seizures (PNES) - the seizures can look the same and have the same features. Despite the impressive increase in our biomedical knowledge it is difficult for neurologists to differentiate between these seizure conditions; and many of the tests used cannot, on their own, confirm a diagnosis. However, it is crucial to get the diagnosis right because the choice of treatment critically depends on the cause and nature of the seizures. Consequently, history-taking and the interaction between patient and doctor remains key to the investigation and correct and effective treatment of epilepsy and PNES.

Recent research indicates that the close examination of doctor-patient encounters not only enables us to identify linguistic and interactional features that help with the diagnosis of epilepsy and PNES, but also yields helpful psychological insights into how people with seizures experience their disorder. Previous work has alerted researchers (and neurologists) to the important role that references to others not present during consultations (third parties) can play. However, previous studies have not examined or described the use of these third party references in detail. This thesis investigates the use of third party references and seizure witness accounts by participants experiencing refractory seizure disorders using secondary data collected during 20 one-to-one doctor-patient consultations.

Moreover, patients are routinely invited to bring seizure witnesses and companions along to their first as well as to subsequent visits to seizure clinics. Despite the important diagnostic roles companions are thought to play in these encounters, no previous studies have focussed specifically on their contribution to the interaction between patients and health professionals. To help advance what is known about accompanied interactions in the seizure clinic, 50 patients attending a specialist outpatient seizure clinic consented to participate in an observational study.

Findings from this research, funded by the charity *Epilepsy Action*, help inform existing models of interactional criteria that distinguish between the linguistic and communicative features of PNES and epilepsy patient seizure descriptions. The findings suggest that doctors utilising the differential interactive, linguistic and topical features of seizure patient talk need to carefully consider how they conduct and structure these consultations, and recommendations are offered in this respect. Finally, avenues of future research are discussed.

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Declaration of Originality

In accordance with the University regulations, I hereby declare that I am responsible for the work submitted in this thesis, that the original work is my own, and that neither the thesis nor the original work contained therein has been submitted to this or any other institution for a higher degree.

A version of Chapter three has been published in the journal *Seizure: The European Journal of Epilepsy* and a version of Chapter five has been published in the journal *Epilepsy and Behavior*.

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Chapter one: Introduction

1. Introduction

Psychogenic non-epileptic seizures (PNES) are defined by their superficial resemblance to epileptic seizures. However, unlike epileptic seizures, PNES are not the result of abnormal electrical discharges in the brain, but are generally interpreted as physical manifestations of psychological distress and the result of dissociative processes (Reuber, 2008). Given the similarities in the visible manifestations of epileptic seizures and PNES, the differentiation between these two seizure disorders can be difficult, even for the most experienced clinicians. However, it is crucial to get the diagnosis right because the choice of treatment critically depends on the cause and nature of the seizures. People with epilepsy are treated with anti-epileptic drugs (AEDs), and people with PNES are treated with psychotherapy.

Despite recent progress in imaging technology and improved access to investigations such as video-electroencephalogram (EEG) monitoring, tilt-table tests and implantable electrocardiograph (ECG) recorders, history-taking from patients remains central to the diagnostic process (Angus-Leppan, 2008). Interictal tests such as brain magnetic resonance imaging (MRI) and EEG can show nonspecific changes or appear normal in over two-thirds of patients presenting after an unprovoked epileptic seizure (Angus-Leppan, 2008 and Kotsopoulos, de Krom and Kessels, 2003). The same tests can show (unexpected) abnormalities in more than one-fifth of patients with PNES (Reuber et al, 2002a). In addition, (expensive) video-EEG telemetry captures typical events in only one-half to two-thirds of patients referred for testing (Benbadis et al, 2004; Ghougassian et al, 2004 and McGonigal et al, 2004).

To date, only a modest number of studies have focussed on the diagnostic value of different aspects of history-taking when patients present with transient loss of consciousness. For instance, it has been shown that clusters of factual items (such as the presence of presyncopal symptoms or postictal confusion) can differentiate well between epileptic seizures and syncope (Kotsopoulos, de Krom and Kessels, 2003; Sheldon et al, 2002 and Hoefnagels et al, 1991). However, it is not clear that this approach works reliably for the differentiation of epilepsy and PNES. For example, a number of studies have demonstrated that

some clinical features traditionally used by doctors to inform their diagnosis (such as seizures from sleep or pelvic thrusting) have no predictive value (Geyer, Payne and Drury, 2000 and Duncan et al, 2004).

In view of this, it is perhaps not surprising that studies in different clinical settings have identified misdiagnosis rates ranging from 5 to 50% (Benbadis et al, 2004; Scheepers, Clough and Pickles, 1998; Howell, Owen and Chadwick, 1989 and Smith, Defalla, and Chadwick, 1999), with an average estimated as ranging between 20% and 30% (Stokes et al, 2004). Most patients with PNES are initially thought to have epilepsy, and it typically takes several years for the correct diagnosis of PNES to be made (De Timary, Fouchet, and Sylin, 2002 and Reuber et al, 2002b). This means that many patients are exposed to inappropriate, ineffective and potentially dangerous drug treatments that may actually exacerbate their condition, cause iatrogenic injury or even death (Trimble, 1982; Benbadis, 1999 and Reuber et al, 2004). It is also important to consider the cost implications of misdiagnoses. The total treatment cost attributable to erroneous diagnoses of epilepsy has recently been estimated to be £138 million per year for NHS and social care services in England and Wales alone (Juarez-Garcia, Stokes and Shaw, 2006).

The research presented in this thesis is part of a multidisciplinary programme of study involving sociologists, linguists and neurologists at the Universities of Sheffield and York (UK). Building on previous work using an approach derived from Conversation Analysis (CA) and carried out in Bielefeld, Germany (Guelich and Schoendienst, 1999; Schoendienst, 2001; Furchner, 2002 and Surmann, 2005, cited in Schwabe et al, 2008), the programme aims to improve the effectiveness of the history-taking process for the purpose of distinguishing between epileptic seizures and PNES.

So far researchers have demonstrated that the observations made in conversations with German patients can be replicated in English clinical encounters (Schwabe, Howell and Reuber, 2007), that patients with epilepsy and PNES use different metaphoric conceptualisations for their seizure experiences (Plug, Sharrack, and Reuber, 2009b and Plug, Sharrack, and Reuber, 2011), that they prefer different labels for their seizures (Plug, Sharrack, and Reuber, 2009c) and that patients with epilepsy are more likely to volunteer subjective accounts of seizure symptoms than patients with PNES

(Plug, Sharrack, and Reuber, 2009a). Furthermore, a prospective multi-rater study has confirmed the diagnostic potential of linguistic, topical and interactional observations in the seizure clinic setting (Reuber et al, 2009).

A comprehensive review of this (and wider) literature is presented in chapter two of this thesis. The review identified and synthesized research that explored linguistic, interactive and topical features of how patients with epilepsy and patients with PNES describe their seizure experiences, and distinguishing differences between these. However, the principal goal of the review was to investigate the differential potential of references to others not present in consultations (third parties).

Previous work has alerted researchers (and neurologists) to the important role that references to people who are not present during the conversation can play, and suggested that a focus on third party references could uncover further linguistic observations that could help with the differential diagnosis of epilepsy and PNES. People with seizures who talk to their doctor often refer to others who are not present. However, previous studies have not examined or described the use of these third party references in detail. The empirical chapter presented in chapter three of this thesis investigated the use of third party references by participants experiencing refractory seizure disorders in 20 one-to-one doctor-patient consultations ('interviews') with a neurologist at the Royal Hallamshire Hospital (Sheffield, UK) using (qualitative) content analysis methods.

National guidelines and studies focusing on the risk of misdiagnosis underline the importance of obtaining descriptions not only from patients but also from witnesses of attacks, and describe the difficulties clinicians face when adequate witness accounts are unavailable (NICE, 2012; Leach et al, 2005; Smith, Defalla and Chadwick, 1999 and Chowdhury, Nashef and Elwes, 2008). Consequently, accompanying persons often play a key role in diagnostic encounters between doctors and patients with attacks.

Healthcare professionals may also rely on family, friends and caregivers to help patients come to terms with a new seizure diagnosis. Post-diagnosis, companions are often involved in helping to mitigate seizure-related risks and ensuring that patients access appropriate treatment. In follow-up (community-

based) visits, companions have been observed to facilitate doctor-seizure patient discussions by providing additional information about side-effects and by tracking changes in patients' symptoms over time (Gilliam et al, 2009). For all of these reasons patients are routinely invited to bring a companion – who may be a seizure witness - along to their first as well as to subsequent visits to seizure clinics.

However, despite the important roles companions often play in these encounters, no previous studies have focussed specifically on their contribution to the interaction between patients and health professionals.

A comprehensive review of literature examining the effects of companions in medical interactions is presented in chapter four of this thesis. The findings indicated that in relation to patients' first visits to a seizure clinic, the obvious benefits of having access to a companion's account could be reduced by the loss of diagnostically important information associated with the reduction of the patient's discourse space. The loss of patient discourse space is particularly relevant to seizure (neurology) clinic interactions. Studies demonstrating how patients with seizures talking to the doctor in first clinical encounters can improve diagnostic accuracy are based on the analysis of clinical interviews in which doctors talk to unaccompanied patients with seizures. In these encounters, patients were given time and discourse space to talk about what was most relevant to them. Using the 'EpiLing' interview technique, doctors participating in these studies were expected not to interrupt patients or to introduce new topics (at least in the early parts of these encounters) (Schwabe, Howell and Reuber, 2007 and Schwabe et al, 2008). However, these encounters may not be representative of routine neurology outpatient visits.

To explore the effects of companionship in routine outpatient encounters, 50 patients (aged over 18 years) attending a specialist seizure clinic at the Royal Hallamshire Hospital (Sheffield, UK) between January 2010 and March 2012 were invited to participate in an observational study. All patients had been asked in their invitation letter to bring along a witness of their attacks if possible. Patients were eligible for inclusion if they had been referred to the clinic because of seizure disorders of uncertain aetiology for an initial consultation with one of three consultant neurologists whom they had not met previously. Consecutive eligible patients (and where applicable their companions) were

invited to take part, and if they agreed provided written informed consent to participate. Doctors participating in these interactions were not encouraged to alter their consultation style, and were instructed to use their routine 'interview' method.

The empirical study presented in chapter five of this thesis explored differences in the duration and structure of these unaccompanied (dyadic: patient and physician) and accompanied (triadic: patient, physician and one companion) initial (diagnostic) consultations. The study advanced what is known about these interactions by exploring associations between participant discourse spaces, and the strength, direction and significance of these 'structural' (discourse space) correlations.

However, the analysis presented in chapter five did not address the interactive (communicative) behaviours of companions per se, nor the effects of companion descriptions and interactions on those of patients. The interactive behaviours of seizure witness companions may reduce the diagnostic yield and/or the differential potential of the interactional, linguistic and topical markers of seizure patient talk observed in one-to-one doctor-patient interactions. On the other hand, there may be conversational diagnostic pointers in the contributions of companions to these encounters, or doctors' observation of the interaction between patients and companions, that could yield data of differential diagnostic significance (such as the head-turning sign described in the dementia clinic) (Bouchard and Rossor, 1996). To date all studies that have examined patients' and witnesses' accounts of seizures have focussed on factual content (Mannan and Wiesmann, 2003 and Reuber et al, 2011) and no previous studies have looked at these aspects of communication in the seizure clinic.

The final empirical analysis, presented in chapter six of this thesis, explored the effects of companions in a sample of thirteen consultations with epilepsy patients and PNES patients accompanied by a seizure-witness spouse or partner. To gain a more holistic picture of companion involvement in these interactions mixed methods were employed. Researchers have called for methods that include multiple approaches in order to study the multiple levels at which exchanges of meaning occur in accompanied interactions (Coe and Prendergast, 1985). In the analysis, the structure, context, sequence, form and

content of interactions were analysed using quantitative and mixed qualitative methods.

In the analysis, the verbal activities of participants were quantified and associations between participants' discourse spaces were assessed. Building on this analysis, the topical content and history-taking phases of the consultations were explored. Similarities and differences between the discourse space 'structures' and topical content of the PNES and epilepsy patient consultations were evaluated. Thereafter, Conversation Analysis (CA) inspired Discourse Analysis (DA) methods were used to examine differences in how PNES and epilepsy patient companions became involved in the interactions to describe what they had seen, the resistance displayed by epilepsy and PNES patients when asked to describe their seizure episodes, and the reliance placed on the companions of PNES and epilepsy patients to describe what they had witnessed. In the final phase of analysis, the effects of companionship (and the interaction of doctors) on a recognised differential feature of seizure patient talk, subjective seizure symptoms, was explored.

In the concluding chapter of the thesis (chapter seven), findings from the research project were considered in the context of study limitations, the implications for clinical practice, and avenues of future research.

1.1 Ethical consent and regulatory approval

The South Sheffield NHS Research Ethics Committee gave ethical approval for all studies described in this thesis. Research Governance approval was also granted by the Sheffield Teaching Hospitals NHS Trust. The University of York Ethics Committee ratified NHS approval. All patients gave informed consent prior to the recording of encounters.

Chapter two: The differential potential of interactional features in seizure patient talk - a comprehensive review of the literature.

1. Introduction

Despite huge advances in biomedical technologies, differentiating between PNES and epilepsy remains a difficult task for clinicians, and misdiagnosis rates are high. As discussed, tests such as MRI and EEG have been shown to show non-specific changes, appear normal or show (unexpected) abnormal changes that do not accord with a clear-cut diagnosis of epilepsy or PNES (Benbadis et al, 2004; Ghougassian et al, 2004; McGonigal et al, 2004 and Reuber et al, 2002b). Similarly, the applicability of video-EEG test results crucially depends on patients experiencing a (typical) seizure during the test. Studies have shown that over one- third of patients do not experience a seizure whilst undergoing video-EEG testing (Angus-Leppan, 2008 and Kotsopoulos, de Krom and Kessels, 2003). These studies exclude those patients that experience seizures so infrequently that referral for (expensive) video-EEG was not a feasible option.

It is not surprising then that history taking is a crucial task for neurologists in these diagnostic encounters. When trying to differentiate between PNES and epilepsy, neurologists may be wholly dependent on their interpretation of the patient's history and *what* the patient has to say about their attacks (Reuber, 2008). However, as pointed out, many clinical features (factual items) traditionally used by neurologists to delineate between patient descriptions of attacks (for example, tongue biting, incontinence, pelvic thrusting) have been shown to have little, if any, diagnostic value (Geyer, Payne and Drury, 2000 and Duncan et al, 2004).

A group of researchers at Bethel Epilepsy Centre and the University of Bielefeld in Germany observed that differences between *how* people with PNES and epilepsy describe their attacks might help neurologists to differentiate between epilepsy and PNES. Working under the banner of the 'EpiLing' project, the team discovered that PNES and epilepsy patients had distinct communication profiles and there were interactive differences between how people with PNES and people with epilepsy described their seizure experiences.

Following the work of the 'EpiLing' project a group of neurologists, sociologists and linguists at the University of Sheffield (UK) developed the 'Listening to people with seizures' project. The initial aim of the project was to see if findings from the German 'EpiLing' data could be replicated in an English language population. Finding this was the case, the team subsequently explored the diagnostic differential potential of a number of topical, interactive and linguistic differences between how people with epilepsy and PNES describe their experiences.

1.1 Aims and objectives

This review aimed to identify and assess studies that have examined the interactive features of seizure patient talk. Particularly, those studies that have explored differences between *how* people with epilepsy and PNES describe their attacks.

An overview of the literature identified for inclusion in this review is presented in the results section. This is followed by a description of the methods developed by the 'EpiLing' and 'Listening to people with seizures' project teams to collect and analyse data. Based on the findings of the 'EpiLing' and 'Listening to people with seizures' projects, typical communication profile summaries of epilepsy and PNES patients are offered.

These and other findings from the literature are discussed in more detail under thematic headings that encapsulate the distinguishing features of seizure patient talk: 'Initiation and focus', 'Description of periods of reduced consciousness and self-control', 'Subjective seizure symptoms', 'Formulation effort', 'Seizure metaphors', 'Labelling', 'Emotional displays' and 'Coping styles'.

To date, 'EpiLing' and 'Listening to people with seizures' project data have been drawn from initial (diagnostic) consultations with a neurologist and a seizure patient present. Researchers and neurologists have observed that patients often refer to others not present (third parties) when they describe their attacks; for example, by reporting what a seizure witness had told them about an episode. Findings from the projects have hinted at the observation that differences between how patients reference third parties when describing their attacks may have differential diagnostic potential.

A further aim of this review was to identify research that has investigated differences between how people with PNES and epilepsy reference others not present (third parties) when they describe their seizure experiences, and to assess the differential potential of these references. These findings are presented under the banner, 'Third party references' in the results section of this chapter.

For the discussion, results from the review were organised into two main themes (that were thematically derived from the data), 'Interactional resistance' and 'Subjective capacity'. The discussion concludes with an examination of the diagnostic potential of third party references with reference to these two themes.

Following this discussion, limitations of the review are described. In the conclusion, the differential diagnostic potential of interactive, linguistic and topical differences of seizure patient talk are considered, and possible avenues of future research concerning how people with epilepsy and PNES use third party references when they describe their attacks are offered.

The methods used to identify literature relevant to these aims and objectives are presented below.

2. Methods

A scoping review was undertaken before a full literature review search was performed. Findings from the scoping exercise helped to inform the methods used to conduct the full review. The impact of scoping review findings on the subsequent limitations imposed as part of the review design is discussed.

2.1 Criteria for inclusion and exclusion

The primary objectives of the study had to include an 'interactional' exploration of seizure patient descriptions of attacks. That is, an examination of how people with (epileptic or PNES) seizures describe their seizure experiences.

The scoping review identified a considerable amount of literature that explored the differential potential of factual seizure items in seizure patient descriptions of their attacks (for example, incontinence, tongue biting, pelvic thrusting, vocalisations). However, a comparatively small amount of research was identified that explored how both people with PNES and epilepsy described their seizure experiences. Consequently, the decision was made to incorporate studies into the review that included exploration of only one group of seizure patients – that is, it was not necessary that studies included both people with epilepsy and people with PNES, the inclusion of one of these groups was also permissible. In addition, with the exception of acute care environments, study setting was disregarded as an inclusion characteristic.

Acute care settings (such as Accident and Emergency departments) are considered unique medical environments, in which unique interactions take place (Simpson et al, 1991). As such, studies taking place in these settings were excluded from this review.

Similarly, studies exclusively exploring epilepsy and/or PNES in the context of serious co-morbid psychological illnesses, physical disorders, significant learning disabilities, or pre and/or post major neurological surgical intervention were excluded.

Some of the studies identified during the scoping review exclusively included participants with serious co-morbid psychological illnesses, physical disorders or learning disabilities. A number of studies were also identified that explored patient outcomes (for example, language use and ability and Quality of Life (QoL) indicators) pre and/or post major neurological surgical intervention.

It is well established that psychiatric comorbidities exist in PNES (Reuber 2009 and Bodde et al, 2009) and epilepsy patient populations (Gaitatzis et al, 2004). Similarly, the prevalence of comorbid physical disorders is higher in seizure patient populations compared to the general population and healthy controls (Strine et al, 2005).

However, during the scoping review studies were identified that exclusively included samples of PNES and/or epilepsy patients with serious co-morbid psychological illnesses (for example, schizophrenia) or physical disorders (for

example, Alzheimer's disease). In the main, these studies were cluster analyses (and predominantly epidemiological in nature), or the studies examined sub-groups of seizure patients with these comorbidities in relation to other variables (for example, treatment outcomes). None of these types of studies identified during the scoping exercise met the criteria of exploring the 'interactional' features of seizure patient descriptions of attacks. Nevertheless, in the event that applicable literature was identified in the full search, it was decided that studies that exclusively included seizure patients with serious psychiatric or physical comorbidities should be excluded. Had these types of studies been included in the review, it was considered that review findings might not reflect those of standard epilepsy and PNES seizure populations.

Similarly, studies of patients with significant learning difficulties were excluded from the review. These groups of patients have routinely been excluded from research that has explored interactional differences in how people with epilepsy and PNES describe their attacks, as was the case in studies arising from the 'EpiLing' and 'Listening to people with seizures' projects. This exclusion criterion was also applied to the fifty participants described in chapters five and six of this thesis. People with learning disabilities typically demonstrate different language abilities and interactive traits than those without learning disabilities. They may also require a family member, friend, carer or technical device to help them communicate. For reasons of comparability, studies of these seizure patient populations were excluded from the review.

More pragmatically, there are also likely to be issues of informed consent to contend with if one wishes to include people with learning disabilities or those with reduced mental capacity in study samples. Certainly, the ethical approval granted by the NHS ethics committee to collect the empirical data presented in this thesis did not allow for those incapable of providing informed consent to participate.

Studies identified during the scoping exercise that included patients that had been assessed for and/or had undergone neurology surgery were frequently observed to use standardized tests of language lateralization pre major neurological surgical intervention to predict and assess postoperative outcomes (such as changes in verbal memory); for example, see Bonelli et al (2010). During the scoping review a fair proportion of studies that explored patient

outcomes following major neurological surgical intervention were identified as including (a variety of) QoL indicators. For example, Markland and colleagues (2000) explored health related QoL outcomes (such as emotional well-being, language, social isolation, health perception, role limitations social and health discouragement, and seizure worry) in a group of patients with medically refractory epilepsy treated with anterior temporal lobectomy (a major neurological surgical intervention). This study included a marginal exploration of the interactive mechanisms used by people with seizures to describe their experiences (attacks). However, it was necessary to exclude these types of studies from the review.

Patients who have undergone major surgical intervention may have language abilities that are not comparable to those that have not undergone major neurological surgical intervention. As Motamedi and Meador (2003) have pointed out, left sided temporal lobectomy (the most common surgical intervention for people with seizures) typically induces verbal memory and learning deficits. In addition, patients that are a candidate for, or that have undergone major neurological surgical interventions, may not be representative of seizure patients as a group in other ways, for example, with regard to the frequency and severity of their seizures.

For reasons of practicality, the search was restricted to literature written in or translated to the English language and published after 1989. No (potentially) relevant literature was identified prior to 1989 during the scoping review. The author's native (only) language is English. Hence, the review was also limited in this respect.

Finally, inclusion criteria required that study participants had to be over 18 years of age, if stated, or be labelled 'adults'. Previous 'EpiLing' and 'Listening to people with seizures' studies only included adult participants. There are significant differences between the communication abilities and techniques of children and adults. In addition, NHS ethical approval for the collection of empirical data presented in this thesis mandated all participants be capable of giving informed consent. For these reasons, only studies that included adult participants were eligible for inclusion in this review.

2.2 Development of a search set

A primary focus of search set development was determining the most appropriate and efficient diagnostic labels to capture the largest yield of relevant literature available. This necessitated experimentation with different diagnostic labels and label combinations, assessment of results, and modification of descriptors as appropriate.

On its own, the label seizure* was found to yield an excessive number of irrelevant hits. The yield was constrained by using the seizure* label as the primary descriptor and stipulating the inclusion of other (more specific) diagnostic labels.

Findings from the scoping exercise indicated that a number of diagnostic labels are used to describe psychogenic non-epileptic seizures. The main diagnostic labels used in the literature were found to be, psychogenic non-epileptic seizures, non-epileptic seizures, non-epileptic attack disorder, and abbreviations PNES, NES and NEAD. The term non*epilep* was used to capture research with non-epileptic attack disorder descriptors. The individual descriptor labels attack*disorder*, attack* or disorder* were excluded from the search set after experimentation suggested inclusion resulted in an excessive number of irrelevant hits (across a diverse spectrum of medical conditions). The label ps*seizure* was applied to capture psychogenic non-epileptic seizure descriptors. This was appropriate as some (of the older) research identified used the diagnostic labels pseudo or psychological seizures. The diagnostic label used to capture epileptic patient samples was simply epilep*; which, when applied during the experimentation process, consistently produced a relevant yield of results.

After considerable experimentation it was decided that the labels and operators seizure* AND epilep* OR non*epilep* OR ps*seizure* OR PNES OR NES OR NEAD could be appropriately applied to describe and capture research including these groups of seizure patients.

Following identification of diagnostic labels to be included in the search set, descriptors were applied to narrow results and capture studies that explored seizure patient descriptions of attacks. Scoping results suggested that authors

use a diverse range of 'interactive' descriptors; consequently, it was decided that the search set should be inclusive rather than exclusive in this respect.

After considerable experimentation, the labels communicat* OR conversat* OR interactional OR description* OR talk* OR discourse were included in the search set. Notably, a truncation operator (asterisk) was not used with the 'interactional' label and it was constrained in this respect. This was appropriate as use of the descriptors interact* and interaction* yielded an excess of irrelevant results (biological studies). It is also notable that description* could have been truncated at descri* (to include descri(be), descri(bes) and descri(bed)), however, this too resulted in an excessive number of irrelevant hits. Similarly, the label discuss(*) was excluded from the search set for this reason. No criteria were applied to identify studies that focused solely on third party references or specific interactional features, as the scoping exercise revealed the yield of literature would be severely limited.

The use of these descriptors resulted in the final search set: seizure* AND epilep* OR non*epilep* OR ps*seizure* OR PNES OR NES OR NEAD AND communicat* OR conversat* OR interactional OR description* OR talk* OR discourse.

2.3 Search strategy

Using the aforementioned search set the key science databases searched were: Education Resources Information Centre (ERIC), Applied Social Sciences Index and Abstracts (ASSIA), Excerpta Medica Database (EMBASE), PubMed, CSA Linguistics and Language Behaviour Abstracts, Cumulative Index to Nursing and Allied Health Literature (CINAHL), MEDLINE, CSA Sociological abstracts, and the Social Science Citation Index (ISI) Web of Knowledge.

A prefix was incorporated to search database 'topics' when possible. However, where this option was not available a prefix to search the abstract, title and/or key words of the literature was adopted. Where databases included psychological and social science literature search options the 'all sciences' search option was applied. Finally, the ancestry method (searching the reference sections of identified literature) was employed to find relevant literature that had not been identified during the database searches.

All databases were searched in May 2010. The Social Science Citation Index (ISI) Web of Knowledge (that proved the most fruitful of the databases searched) was revisited in April 2012 and the search replicated to update review results (resulting in one new article identified for inclusion).

3. Results

A total of 16 studies were identified for inclusion in the review. Notably, four (highly relevant) studies written in the German language by the 'EpiLing' project team were excluded (Guelich and Schoendienst, 1999; Schoendienst, 2001; Furchner, 2002 and Surmann, 2005). However, an English language summary of these papers was incorporated (Schwabe et al, 2008). Of the 16 studies identified for inclusion in the review, 13 were empirical studies of epilepsy and/or PNES patient descriptions of their experiences, and three were review pieces.

3.1 Communication profiles of patients with epilepsy and patients with PNES

Much of the literature included in this review follows from the multidisciplinary research findings of the 'EpiLing' project carried out at Bethel Epilepsy Centre and the University of Bielefeld in Germany (Guelich and Schoendienst, 1999; Schoendienst, 2001; Furchner, 2002 and Surmann, 2005). Originally initiated by Dr M Schoendienst, a neurologist in Bethel, collaboration was formed with Dr Guelich, a linguist at the University of Bielefeld. The resulting fruit of this collaboration was the 'EpiLing' project. The primary aim of the project was to discover if people with PNES and epileptic seizures describe their experiences differently, and if differences in the interactional profiles of seizure patients could contribute to the differential diagnosis of these seizure conditions. Written in German, these research papers have been summarised by Schwabe, Reuber, Schoendienst and Guelich (2008) for English language speakers.

The 'EpiLing' project developed a distinct research methodology to investigate the diagnostic potential of how people with epilepsy and PNES describe their seizure experiences. The 'EpiLing' team developed a semi-standardised communication guideline for use in clinical encounters with seizure patients. The authors reported that use of the guideline increases opportunities to identify

diagnostically differential linguistic responses to the same interactional challenges, it enhances the overall comparability of medical encounters, and it helps to ensure that consultations continue to fulfil their clinical (diagnostic) purpose. The communication guideline was based on the analysis of a number of consultations recorded during the pilot phase of the 'EpiLing' project and, as such, was 'derived from the data' (Guelich and Schoendienst, 1999; Schoendienst, 2001; Furchner, 2002 and Surmann, 2005, cited in Schwabe et al, 2008).

Known hereafter as the 'EpiLing' interview method, the most significant differences between the interview procedure and traditional history taking are that the doctor's contributions are restricted to encourage the patient to develop their own communicative agenda and to maximize their participation in the conversation. The method involves the use of open questions, which give the floor to the patient and can be addressed in a range of ways. Interruptions and direct questions by doctors about clinical features (such as tongue biting, incontinence, etc.) are deliberately discouraged. Interviews begin with an open question, which makes no direct mention of seizures (for example, "what was your expectation when you came here?"). Accounts of individual seizure episodes are then elicited, by asking: "Could you tell me about your first/worst/last seizure?" Finally, the patient is encouraged to elaborate something that s/he has already described, (for example, "You say that you black out in this seizure. Are you completely unconscious when this happens or can you still hear or see what is going on around you?"). During the final phase of the 'interview' (consultation), the doctor is able to ask any clinical questions not already addressed (Guelich and Schoendienst, 1999; Schoendienst, 2001; Furchner, 2002 and Surmann, 2005, cited in Schwabe et al, 2008 and Schwabe, Howell and Reuber, 2007).

Using methods inspired by Conversation Analysis (CA), 'EpiLing' researchers made significant departures from CA methodology during the research process, with the resulting analytic method better resembling something in-between CA and Discourse Analysis (DA). Indeed, the considerable overlap between the linguistic analyses carried out by the team and other types of close linguistic study of human interaction, such as Discourse Analysis, has been acknowledged (Schwabe et al, 2008).

Perhaps one of the most important differences between the methods used and those of conventional CA is that the focus of the analysis is on the linguistic and interactive behaviour of the patient, rather than the interaction between the doctor and patient. In this sense, and as the authors have observed, there is also considerable overlap between the methods used and those of other forms of microanalytic study, for example, narrative analysis (Schwabe et al, 2008).

In addition, the application of CA terminology and operationalization of CA terms in the ('EpiLing' and 'Listening to people with seizures') research carries a broader remit than would be deemed acceptable by many 'hard line' conversational analysts. To give an example, Schwabe et al (2008) reported, "*the expression of reformulation is used descriptively and not in the more narrow CA sense of metacommunicative acts intended to construct an explicit sense of something which has just been talked about*" (p69).

Similarly, to ensure that clinically relevant questions were addressed while the analytic methodology was not overstretched, research questions and methods were developed as the 'EpiLing' project progressed (Guelich and Schoendienst, 1999; Schoendienst, 2001; Furchner, 2002 and Surmann, 2005, cited in Schwabe et al, 2008). In their notes, Schwabe et al (2008) explained that the research procedure used was therefore in line with the interdisciplinary application of discourse analysis methodology.

However, there are parallels between the analytic procedure described and the methods used by conversation analysts. As Schwabe et al (2008) have reported, when the method is used, the opening stages of analysis begin by identifying prominent linguistic and interactive features of seizure experience accounts, using a method akin to that of CA's 'unmotivated looking'. Building on single case analysis, researchers identify and record 'conversational profiles' for each participant. When this process is complete, findings are amalgamated into typical 'conversational profiles' (regardless of patient diagnosis). Finally, typical 'communication profiles' of PNES and epilepsy patients are generated. Using these methods, over 110 transcripts of doctor-seizure patient encounters have been analysed by the 'EpiLing' team (Guelich and Schoendienst, 1999; Schoendienst, 2001; Furchner, 2002 and Surmann, 2005, cited in Schwabe et al, 2008).

'EpiLing' researchers observed that participants typically displayed different 'communication profiles' that could help clinicians differentiate between people with epilepsy and people with PNES.

In their data, patients with PNES typically gave seizure accounts and trajectories that were difficult to understand, they displayed difficulty focusing on specific seizure episodes and trajectories, preferred not to volunteer information about their seizures, tended to use absolute negations when describing phases of reduced self-control and gaps in consciousness, did not tend to volunteer subjective seizure symptoms, offered very short and condensed seizure descriptions, and gave seizure accounts that were inconsistent with their choice of metaphors (Guelich and Schoendienst, 1999; Schoendienst, 2001; Furchner, 2002 and Surmann, 2005, cited in Schwabe et al, 2008).

In contrast, patients with epilepsy typically demonstrated being easily able to focus on specific seizure episodes, they coherently described and reconstructed seizure experiences and trajectories, embedded phases of reduced self-control and gaps in consciousness into the context of their overall seizure experience, recounted subjective seizure symptoms, displayed extensive formulation effort when describing their experiences and used consistent metaphoric conceptualizations when they described their attacks (Guelich and Schoendienst, 1999; Schoendienst, 2001; Furchner, 2002 and Surmann, 2005, cited in Schwabe et al, 2008).

In later work by the 'EpiLing' team, a researcher blinded to diagnosis prospectively tested the communication profiles described above. In a small pilot study of five seizure patient consultations, the analyst generated three out of five diagnoses correctly (Surmann, 2005, cited in Schwabe et al, 2008).

Following the work of the 'EpiLing' team, Dr M Reuber, a consultant neurologist at Sheffield Royal Hallamshire (NHS) Hospital, developed the 'Listening to people with seizures' project. The initial aim of the project was to determine if research findings from 'EpiLing' project data could be replicated in an English language population.

Schwabe, Howell and Reuber (2007) maintained the general methodological framework of the 'EpiLing' project and explored the diagnostic potential of the

interactional and conversational features of seizure patient talk. Eleven consultations between patients admitted to a neurology ward (Sheffield, UK) with epilepsy (n=5) or PNES (n=6) and a neurologist were video-recorded for analysis.

However, despite using the 'EpiLing' interview method, the research differed from 'EpiLing' project procedures in some important respects. For example, patients were only invited to participate in the study if referred by a consultant neurologist uncertain of diagnosis and if their medical history (notes) did not suggest simultaneous occurrence of epilepsy and PNES. In addition, Schwabe, Howell and Reuber (2007) collected data from patients that had attended hospital for extended video-EEG telemetry, whereas diagnoses in the 'EpiLing' research were determined by the neurologist's interpretation of seizure history coupled with interictal EEG and structural brain imaging as appropriate.

Participants in Schwabe, Howell and Reuber's (2007) research had not met the neurologist (interviewer) previously. In addition, participants were assessed to make sure that they did not have any significant learning disability and that they had not been previously assessed for epilepsy surgery. In their summary of 'EpiLing' project findings, Schwabe et al (2008) do not report if participants in the German data met these criteria.

Finally, in contrast to the broad analytical stance of the 'EpiLing' project, that used a process of 'unmotivated looking', it is notable that Schwabe, Howell and Reuber's (2007) research (akin to that of Surmann's, 2005, cited in Schwabe et al, 2008) was hypothesis driven.

Remaining blinded to diagnosis and using a hypothetical model based on the findings of the 'EpiLing' project, an analyst was asked to predict the correct diagnosis of eleven seizure patients. Following the findings of the 'EpiLing' project, differential features included: initiation of seizures as a topic of discussion, focus on seizure descriptions, seizure description by negation, description of periods of reduced consciousness or self-control, metaphorical conceptualisation of seizures, discussion of subjective seizure symptoms, formulation work associated with seizure descriptions, and spontaneous references to attempted seizure suppression. Despite the modifications to the original protocol, the authors confirmed that previous findings from the 'EpiLing'

project data were translatable to an English speaking population, and a linguist predicted a diagnosis of epilepsy or PNES correctly in all eleven cases (Schwabe, Howell and Reuber, 2007).

Additional prospective testing soon followed. In an expanded version of the data set described above, Reuber et al (2009) sought to explore whether the qualitative approach used in previous studies could be translated into a diagnostic scoring aid (DSA).

Twenty participants that carried an uncertain diagnosis of epilepsy or PNES were admitted to a neurology ward (Sheffield, UK) for video-EEG monitoring. Using the 'EpiLing' interview method, participants were interviewed by a neurologist whom they had not met previously. The interactions were video-recorded and lasted an average of 25 to 30 minutes each. Patients were assessed to make sure that they did not have a significant learning disability and were fluent in English. Patients were not allowed to participate in the study if they had been assessed for epilepsy surgery. A diagnosis of epilepsy or PNES was proven with 'gold standard' video-EEG monitoring. That is, all participants experienced a seizure during video-EEG monitoring that was considered typical by patients and witnesses of habitual attacks. A neurologist with no involvement in the research project confirmed the diagnosis of epilepsy or PNES using video-EEG test results in conjunction with other available clinical data.

Formulating a DSA from linguistic and interactional features that had previously been described as having differential diagnostic value (Guelich and Schoendienst, 1999; Schoendienst, 2001; Furchner, 2002 and Surmann, 2005, cited in Schwabe et al, 2008 and Schwabe, Howell and Reuber, 2007), the resulting scoring table consisted of 17 features that were divided into three sections (interactional, topical and linguistic features) (Reuber et al, 2009). Research protocol dictated that two linguists blinded to diagnosis try to predict the confirmed medical diagnosis (established by video-EEG) of participants using the DSA. The significance of individual features (items) for correct classification, overall diagnostic scores, and the sensitivity, specificity, and inter-rater reliability of the model were calculated.

The primary function of the interactional features section of the DSA was to assess the extent to which information was volunteered by the patient or initiated by the doctor across several features: the general focus on seizure experience, description of subjective seizure symptoms, description of attempts at seizure suppression, description of phases of reduced self-control ('gaps' in consciousness), response to challenge of accounts of phases of reduced self-control ('gaps'), and description of individual seizure episodes (Reuber et al, 2009).

The second section of the DSA explored topical features of patient seizure descriptions. Focusing on descriptions of phases of reduced self-control ('gaps'), raters were asked to assess how patients reconstructed 'gaps' in consciousness and contoured 'gaps' in seizure trajectory (Reuber et al, 2009).

The final section of the DSA explored the linguistic features of patient talk; raters were asked to assess items against the amount of formulation effort displayed by patients and metaphoric conceptualisations of their seizure episodes. Items assessed in this section consisted of patient descriptions of subjective seizure symptoms, negations in description of seizure experiences, formulation effort associated with the description of 'gaps', metaphoric conceptualisation of seizures, external and internal conceptualisations of seizures, and conceptualisation of seizures as a fight or struggle (Reuber et al, 2009).

For ease of reference, an adapted version of the DSA communication guideline used in the study can be found in the Appendix (see, figure 1: Communication guideline to accompany the DSA). In addition, a scoring table detailing the DSA items, observation summaries, and the significance of each item for correct classification is also presented in the Appendix (see, table 1: DSA item summary).

Application of the model produced impressive results. Of the 20 participants, seven were diagnosed with video-EEG as having epilepsy and 13 were diagnosed with PNES. Using the DSA, the linguists predicted 85% (17 out of 20) of diagnoses correctly. Moderate to good inter-rater reliability (k 0.59) was demonstrated, with a sensitivity of 85.7% (71.4%) and a specificity of 84.6% (92.3%) reported. What is more, differences in the mean DSA scores were

significant for both raters (rater 1: $p=0.017$, rater 2: $p=0.047$). As the authors observed, the results of the experiment were more remarkable considering that only 40% of the participants carried a correct diagnosis before admission for video-EEG. In addition, the inter-rater agreement achieved by the two linguists using the DSA stood up against more objective methods such as EEG testing (Reuber et al, 2009).

As well as assessing the differential features identified in previous qualitative research (Schwabe, Howell and Reuber, 2007 and Schwabe et al, 2008), and those quantitatively assessed using the DSA (Reuber et al, 2009), members of the UK ('Listening to people with seizures') team have explored other features of seizure patient talk.

Recent research has explored the differential use of seizure labels (Plug, Sharrack and Reuber 2009c) and the different metaphors used by patients to describe their seizures (Plug, Sharrack and Reuber, 2009b and Plug, Sharrack and Reuber, 2011). The differential potential of seizure patient communication profiles has also been examined in more depth in a case comparison paper (Plug, Sharrack and Reuber, 2009a). In addition, the coping styles displayed by epilepsy patients in these clinical encounters have been examined (Reuber and Monzoni, 2009). Finally, a review published in 2009 amalgamated the team's research findings (to date) and their applicability to clinical practice, for a professional (clinical) audience (Plug and Reuber, 2009).

As the research findings briefly presented here suggest, the differential features of seizure patient talk have been successfully used to predict epilepsy and PNES diagnoses in different seizure patient samples. The individual features of these communication profiles, subsequent research findings by the UK team, and findings from other literature included in this review are discussed in more detail below.

3.2 Initiation and focus

Research has shown that people with epilepsy typically initiate seizure descriptions as a topic of discussion and volunteer descriptions of their seizure experiences. In addition, that they typically demonstrate being easily able to focus on seizure descriptions and provide coherent accounts of individual seizure episodes (Guelich and Schoendienst, 1999; Schoendienst, 2001; Furchner, 2002 and Surmann, 2005, cited in Schwabe et al, 2008; Schwabe, Howell and Reuber, 2007; Plug and Reuber, 2009 and Plug, Sharrack and Reuber 2009a).

In comparison, people with PNES have typically been observed to avoid initiating seizures as a topic of discussion. Interviewers (neurologists) have reported the need to prompt patients with PNES to discuss their seizure experiences. Authors have also observed that people with PNES typically demonstrate difficulty focusing individual seizure episodes and that they provide (incoherent) accounts of seizure episodes that are difficult to understand (Guelich and Schoendienst, 1999; Schoendienst, 2001; Furchner, 2002 and Surmann, 2005, cited in Schwabe et al, 2008; Schwabe, Howell, and Reuber, 2007 and Plug, Sharrack and Reuber 2009a).

Broadly labelled 'focusing resistance', these interactional features proved diagnostically significant across a number of features in the predictive multi-rater study carried out by Reuber and colleagues (2009). The hypothesis that patients with epilepsy typically volunteer (introduce) seizures as a topic of discussion, in comparison to patients with PNES who usually avoid these discussions and direct conversation towards other (external) aspects of seizures, such as the possible causes or consequences of seizures, was tested.

For item 1 ('General focus on seizure experience'), patients were assessed as having epilepsy if they volunteered seizures as a topic of discussion early in the 'open phase' of the interview. If the interviewer introduced seizures as a topic of discussion and the patient subsequently discussed their experiences a nil (neutral) score was applied. That is, the observation did not contribute to a diagnosis of epilepsy or PNES. If the interviewer introduced seizures as a topic of discussion, and the patient did not go on to discuss their seizure experiences (for example, they directed focus away from what they experienced during an

attack), the patient was rated as having PNES. In the study, this item was of significance for correct classification for one rater (p0.037).

In the study, item 6 ('Description of individual seizure episodes') was also found to be of significance for correct classification for one rater (p0.041). The item asked raters to assess the focusing resistance displayed by patients when they described individual seizure episodes. 'Description' referred to descriptions of seizures that included subjective accounts. Patients were assessed as having epilepsy if they volunteered a coherent description of an individual seizure episode. If the patient did not volunteer a coherent description of an individual seizure episode, but seemed unable to distinguish between different episodes when prompted, a nil (neutral) score was applied. This criterion was applied on the basis that both patients with epilepsy and PNES have been observed to indicate that 'all seizures are the same' (Reuber et al, 2009). Patients were rated as having PNES if they did not volunteer a coherent description of an individual seizure episode and if they did not explicitly deny the ability to distinguish between seizure episodes when prompted to describe an individual episode.

Initiation and focusing resistance also featured in two other DSA items in the multi-rater study. Patients were rated as having PNES if they did not volunteer, or failed to elaborate when prompted, descriptions of phases of reduced self-control ('gaps') (item 4) and descriptions of subjective seizure symptoms (item 2). In the study, each of these items proved significant for correct classification for at least one rater. These items are discussed in more detail later (see, 'Description of periods of reduced consciousness and self-control' and 'Subjective seizure symptoms').

These diagnostically differential features of seizure patient talk (initiation of seizure descriptions and the ability to focus on seizure descriptions) are supported by other research identified for inclusion in this review.

Watson et al (2002) observed that people with epilepsy were more likely to offer spontaneous seizure narratives compared to people with PNES, albeit in a very different setting and context from the clinical studies described above. In a study of seizure patients' experience of earthquakes in the Seattle metropolitan area (February 2001), Watson et al (2002) observed that when interviewed,

23% of participants with epilepsy (n=26) spontaneously stated that they initially thought they were having a seizure, whereas none of the PNES patients (n= 22) did so (p0.003).

Similar findings are reflected in a study that explored the coping skills of people with epilepsy. Data from nine initial (diagnostic) consultations, in which the 'EpiLing' interview method was used, were analysed using methods underpinned by CA (Reuber and Monzoni, 2009). Epilepsy patients were typically observed to volunteer seizure descriptions, detail the process of how they discovered their disorder (prior to any prompting from the doctor) and to coherently describe individual seizure trajectories (Reuber and Monzoni, 2009).

In addition, studies have found that people with PNES typically display difficulty coherently describing the trajectory of their condition. Green et al (2004) conducted semi-structured interviews and studied the transcripts of nine PNES participants in relation to Leventhal's self-regulation or common sense model. Using an approach from interpretative phenomenological analysis (IPA), the authors found that the PNES participants were often confused about their experience, and consequently found it difficult to express clear ideas about the time-line of their illness. Findings from PNES literature reviews have also indicated that people with PNES typically resist focusing on attacks and find it difficult to report seizure events (Lacey, Cook and Salzberg, 2007; Reuber, 2008 and Plug and Reuber, 2009).

3.3 Description of periods of reduced consciousness and self-control

Periods of reduced control, often signalled by a lack of responsiveness or awareness, encapsulate one of the key features of seizure episodes: reduced consciousness and/or loss of consciousness. The differential diagnostic potential of descriptions of these phases was of particular importance in the German ('EpiLing') data (Guelich and Schoendienst, 1999; Schoendienst, 2001; Furchner, 2002 and Surmann, 2005, cited in Schwabe et al, 2008). Referred to as 'gaps' in the English data, descriptions of periods of reduced consciousness and self-control have also been an area of scrutiny in the UK ('Listening to people with seizures') data (Schwabe, Howell, and Reuber, 2007; Plug and Reuber, 2009 and Plug, Sharrack and Reuber 2009a).

Research findings suggest that the description of 'gaps' can be a challenging task for seizure patients, who may have little, no, or reduced recollection of these periods. Despite the difficulty associated with descriptions of these 'gaps', people with PNES and epilepsy have been observed to tackle the task of reconstructing and describing periods of reduced consciousness and/or loss of consciousness very differently (Guelich and Schoendienst, 1999; Schoendienst, 2001; Furchner, 2002 and Surmann, 2005, cited in Schwabe et al, 2008; Schwabe, Howell, and Reuber, 2007; Plug and Reuber, 2009; Plug, Sharrack; Reuber 2009a and Reuber et al, 2009).

Findings from qualitative studies of doctor-seizure patient interactions have shown that people with epilepsy usually initiate discussions about periods of reduced consciousness and self-control ('gaps'), and demonstrate a willingness to learn what has happened during these periods. For example, by referring to witness reports in order to fill in gaps of their own recollections. People with epilepsy have also been shown to try and precisely place loss of consciousness within the overall context of a seizure episode. As part of this process, they have been observed to contour gaps in consciousness, for example, by describing the last thing they remembered before the 'gap' and the first thing they remembered after the 'gap'. In this sense, people with epilepsy have been described as embedding 'gaps' in consciousness in the overall contexts of seizure episodes, and as presenting loss of consciousness (the 'gap') as just one part of the seizure experience (Guelich and Schoendienst, 1999; Schoendienst, 2001; Furchner, 2002 and Surmann, 2005, cited in Schwabe et al, 2008; Schwabe, Howell, and Reuber, 2007; Plug and Reuber, 2009 and Plug, Sharrack and Reuber 2009a).

When attempting to reconstruct gaps in consciousness, people with epilepsy have been observed to demonstrate rigorous formulation work and to describe their subjective seizure symptom experiences (what they felt or thought) during phases of reduced self-control. Research has also shown that people with epilepsy usually try to distinguish between different grades of consciousness, and take great care doing this (for example, by including subjective symptoms in their accounts and displaying extensive formulation work). Likewise, authors have observed the degree of consciousness experienced by people with epilepsy can usually be challenged interactively. People with epilepsy have typically been found to elaborate on, or to reformulate previous descriptions of

'gaps' in consciousness when prompted by a doctor to do so (Guelich and Schoendienst, 1999; Schoendienst, 2001; Furchner, 2002 and Surmann, 2005, cited in Schwabe et al, 2008; Schwabe, Howell, and Reuber, 2007; Plug and Reuber, 2009 and Plug, Sharrack and Reuber 2009a).

In comparison, people with PNES have typically been observed to present periods of reduced consciousness and self-control ('gaps') as the most defining element of seizure episodes. People with PNES have been described as providing 'holistic' descriptions of periods of reduced self-control and 'gaps' in consciousness. In this sense, authors have noted that people with PNES usually equate 'gaps' in consciousness as synonymous with the seizure experience, as opposed to just one part of the overall experience (Guelich and Schoendienst, 1999; Schoendienst, 2001; Furchner, 2002 and Surmann, 2005, cited in Schwabe et al, 2008; Schwabe, Howell, and Reuber, 2007; Plug and Reuber, 2009 and Plug, Sharrack and Reuber 2009a).

In the German research, the term 'holistic' was applied to descriptions of attacks where the 'gap' was presented as the only aspect of the experience (Furchner, 2002, cited in Schwabe et al, 2008). In their qualitative analyses, UK based researchers expanded the meaning of 'holistic'. Using their definition, broad statements about periods of reduced consciousness that lacked detail (for example, *'I'm out'*, *'I just go'*) were deemed 'holistic' when the 'gap' was presented as a prominent feature of the seizure experience (Schwabe, Howell, and Reuber, 2007; Plug and Reuber, 2009 and Plug, Sharrack and Reuber 2009a).

Given that people with PNES have typically been found to offer short 'holistic' descriptions of periods of reduced consciousness that lack detail, it is not surprising that PNES patient descriptions of these periods have been described as lacking the rigorous formulation effort and subjective seizure symptoms usually associated with epilepsy patient descriptions of these phases. Similarly, researchers have reported that people with PNES do not typically attempt to 'contour' 'gaps', or to reconstruct 'gaps' using their own recollections of events (Guelich and Schoendienst, 1999; Schoendienst, 2001; Furchner, 2002 and Surmann, 2005, cited in Schwabe et al, 2008; Schwabe, Howell, and Reuber, 2007; Plug and Reuber, 2009 and Plug, Sharrack and Reuber 2009a).

Descriptions of different grades of consciousness have also been noted as practically absent from PNES patient descriptions of their seizure experiences. Likewise, in response to challenges of statements about 'gaps', authors have reported that people with PNES tend not to elaborate beyond 'holistic' statements, often despite being repeatedly prompted by the interviewer to do so. As such, PNES patient descriptions of 'gaps' in consciousness have been described as 'absolute and beyond challenge' (Guelich and Schoendienst, 1999; Schoendienst, 2001; Furchner, 2002 and Surmann, 2005, cited in Schwabe et al, 2008; Schwabe, Howell, and Reuber, 2007; Plug and Reuber, 2009 and Plug, Sharrack and Reuber 2009a).

Several DSA items associated with descriptions of periods of reduced consciousness and self-control ('gaps') were tested in the prospective multi-rater study (Reuber et al, 2009).

Item 4 of the DSA ('Description of phases of reduced self-control ('gaps')) asked raters to assess the extent to which participants volunteered descriptions of phases of reduced self-control ('gaps') and how participants responded to interactive challenges about these periods. 'Description' here referred to accounts that included attempts to contour 'gaps' in seizure trajectory, as opposed to brief 'holistic' statements about 'gaps'. Patients were assessed as having epilepsy if they volunteered descriptions of phases of reduced self-control ('gaps') without being prompted by the interviewer to do so. If patients only offered an account of a phase of reduced self-control after being prompted by the interviewer to do so, a nil (neutral) score was applied. Patients were assessed as having PNES if they did not volunteer descriptions of phases of reduced self-control (beyond 'holistic' statements), even when prompted to do so. Using these criteria, one rater in the study found 'descriptions of phases of reduced self-control' significant for correct classification ($p < 0.007$).

However, the extent to which patients responded to interactive challenges of their descriptions of 'gaps' did not prove significant for correct classification for either rater in the study. For DSA item 5 ('Response to challenge of statements about 'gaps)'), raters were asked to assess patient responses to interviewer challenges regarding a prior description of a phase of reduced self-control. Patients were assessed as having epilepsy if they reformulated or elaborated on a previous account. If patients repeated or only offered minimal elaboration

of a previous account, a nil (neutral) score was applied. Patients were assessed as having PNES if they failed to offer a description of a phase of reduced self-control beyond an 'holistic' statement and if they resisted prompting to reformulate or elaborate on a prior ('holistic') account.

However, two items on the DSA that asked raters to assess differences in descriptions of phases of reduced self-control ('gaps') proved to be significant for correct classification for both raters.

Item 9 of the DSA ('Relative importance of 'gaps') asked raters to assess the importance of 'gaps' in the context of the overall description of seizure episodes. Patients that presented 'gaps' in consciousness as just one of several elements of their seizure experiences were rated as having epilepsy. If 'gaps' in consciousness were presented as a prominent feature of seizure episodes, a nil (neutral) score was applied. Patients were rated as having PNES if they presented 'gaps' in consciousness as the most defining element of their seizure experiences. Both raters scored identical results for significance for correct classification for this item ($p=0.008$).

For item 10 of the DSA ('Contouring of 'gaps' in seizure trajectory') raters were asked to assess the extent to which participants contoured 'gaps' in seizure trajectories. Patients were assessed as having epilepsy if there was a clear attempt to contour 'gaps' and if they provided a coherent seizure trajectory. For example, patients described what they experienced before and immediately after 'gaps' and attempted to precisely place the 'gap' in a sequence of events. If a minimal attempt to contour 'gaps' in seizure trajectory was made, a nil (neutral) score was applied. If patients made no attempt to contour 'gaps', relied entirely on witness accounts to do this, and/or failed to offer a coherent seizure trajectory, they were rated as having PNES. This item proved significant for correct classification for rater 1 ($p=0.05$) and rater 2 ($p=0.024$).

Item 11 of the DSA ('Reconstruction of 'gaps') asked raters to assess the extent to which patients were willing to reconstruct events during 'gaps' in individual seizure episodes based on their own recollections or those of seizure witnesses. If patients made a clear attempt to reconstruct 'gaps' based on their own recollections they were rated as having epilepsy. If patients made some attempt (but not a clear attempt) to reconstruct 'gaps' based on their own

recollections a nil (neutral) score was applied. If patients did not make any attempt to reconstruct 'gaps' based on their own recollections, or they relied entirely on seizure witness accounts, they were rated as having PNES. However, this item did not prove significant for correct classification for either rater in the study.

Finally, item 14 of the DSA ('Formulation effort associated with description of 'gaps') asked raters to assess the extent to which patients displayed active formulation effort when they described phases of reduced self-control. This item is discussed in more detail later (under the heading, 'Formulation effort').

3.4 Subjective seizure symptoms

As previously mentioned, the use of subjective seizure symptoms has been described as an important distinguishing feature of epilepsy and PNES patient descriptions of attacks.

Researchers have observed that people with epilepsy typically volunteer subjective seizure symptoms (how they felt and what they thought) and discuss these features in detail when they talk to a doctor about their seizures (Guelich and Schoendienst, 1999; Schoendienst, 2001; Furchner, 2002 and Surmann, 2005, cited in Schwabe et al, 2008; Schwabe, Howell and Reuber, 2007; Plug and Reuber, 2009 and Plug, Sharrack and Reuber 2009a). Similarly, in a study that explored how people with epilepsy coped with their disorder, Reuber and Monzoni (2009) found that epilepsy patients tended to reproduce detailed factual accounts of seizure occurrence coupled with subjective accounts of their seizure experiences.

In comparison, PNES patients have been shown to avoid discussing subjective seizure symptoms (or to discuss these sparingly) when they describe their experiences, often despite considerable prompting from the doctor to do so (Guelich and Schoendienst, 1999; Schoendienst, 2001; Furchner, 2002 and Surmann, 2005, cited in Schwabe et al, 2008; and Schwabe, Howell and Reuber, 2007). In later research, Plug and Reuber (2009) observed that people with PNES did report subjective seizure symptoms, but that without considerable prompting, they tended to focus on other aspects of their seizure experiences, such as the impact of the condition on their lives, or, as was noted

in later research, the dramatic circumstances or consequences of their seizures (Plug, Sharrack and Reuber, 2009a).

Subjective seizure symptoms were central to many of the DSA items in Reuber et al's (2009) multi-rater study. Subjective seizure symptom descriptions were integral to 'seizure experiences' in DSA item 1 ('General focus on seizure experience'), and 'description' in DSA item 6 ('Description of individual seizure episodes') referred to accounts that incorporated subjective seizure symptoms. Other DSA items specifically assessed the differential use of subjective seizure symptoms.

Item 2 of the DSA ('Description of subjective seizure symptoms') asked raters to assess the extent to which patients maintained focus on subjective seizure symptoms (as opposed to other aspects of seizure descriptions, such as seizure causes, effects, and situational details) when they described their attacks. Patients that typically volunteered subjective seizure symptoms when they described their attacks were rated as having epilepsy. If patients only offered subjective seizure symptoms when prompted to do so, a nil (neutral) score was applied. Patients were rated as having PNES if they did not volunteer subjective seizure symptoms and did not discuss or elaborate on these when prompted to do so. In the study, this item proved significant for correct classification for one rater ($p=0.019$).

Assessment of the level of detail attached to descriptions of subjective seizure symptoms (DSA item 7, 'Subjective seizure symptoms') also proved significant for correct classification for one rater in the study ($p=0.038$). If patients described subjective seizure symptoms in 'great detail', they were rated as having epilepsy. If patients described subjective seizure symptoms with 'some or little detail', a nil (neutral) score was applied. If patients listed subjective seizure symptoms but did not describe these beyond brief statements (for example, '*I feel dizzy*', or '*I have a headache*') they were rated as having PNES.

The relative importance of subjective seizure symptoms in descriptions of individual or typical seizure episodes was also tested by Reuber and colleagues (2009). DSA item 8, the 'Relative importance of subjective seizure symptoms', proved significant for correct classification for both raters in the study (rater 1, $p=0.035$ and rater 2, $p=0.038$). For the item, patients were rated as having

epilepsy if subjective seizure symptom accounts were central to their descriptions. A nil (neutral) score was applied when patients paid more or equal attention to the circumstantial details of their experiences (for example, the situations in which seizures took place, the time of the event, factual details about what they were doing before seizures occurred). Patients were rated as having PNES if they did not describe subjective seizure symptoms beyond brief statements, and if these were not considered important (central) to their descriptions of attacks.

Finally, item 12 of the DSA asked raters to assess the extent of formulation effort used by participants to describe subjective seizure symptoms. This item is discussed in more detail below.

3.5 Formulation effort

Authors have observed that both people with epilepsy and PNES may use metadiscursive comments to communicate the ‘indescribable’ things they experience during, before and after seizure episodes. For example, *‘I don’t know how to explain it’* or *‘I don’t have the words to describe what happened’*. However, research has shown that people with epilepsy and PNES typically demonstrate different levels of formulation effort when faced with the difficult task of describing these experiences (Guelich and Schoendienst, 1999; Schoendienst, 2001; Furchner, 2002 and Surmann, 2005, cited in Schwabe et al, 2008; Schwabe, Howell, and Reuber, 2007; Plug and Reuber, 2009 and Plug, Sharrack and Reuber 2009a).

Despite using metadiscursive comments to communicate the ‘indescribable’ nature of their experiences, authors observed that people with epilepsy tended to move beyond the difficulty associated with these descriptions, and strived to communicate what they experienced and how they felt during attacks. To achieve this, people with epilepsy demonstrated rigorous formulation effort (pauses, reformulation attempts, hesitations and restarts) when they described their experiences. In addition, people with epilepsy have been observed to direct ‘checks’ to the interviewer in order to ensure that their (subjective) accounts make sense (for example, *‘do you know what I mean?’* *‘Does that make sense?’*) (Guelich and Schoendienst, 1999; Schoendienst, 2001; Furchner, 2002 and Surmann, 2005, cited in Schwabe et al, 2008; Schwabe,

Howell, and Reuber, 2007; Plug and Reuber, 2009 and Plug, Sharrack and Reuber 2009a).

These findings align with those that suggest people with epilepsy typically contour 'gaps' in consciousness when describing their experiences. As described previously, people with epilepsy have typically been observed to strive to piece together what has happened during 'gaps' in consciousness, to embed these periods in the overall context of their seizure descriptions, and to reformulate or elaborate on descriptions of 'gaps' when prompted to do so. As part of this process, people with epilepsy have been shown to demonstrate rigorous formulation work (Guelich and Schoendienst, 1999; Schoendienst, 2001; and Surmann, 2005, cited in Schwabe et al, 2008; Plug and Reuber, 2009 and Plug, Sharrack and Reuber 2009a).

Furchner (2002, cited in Schwabe et al, 2008) reported that patients (typically those with epilepsy) who presented the 'gap' as just one aspect of their seizure experience and who described the subjective seizure symptoms they experienced during periods of reduced consciousness and self-control, usually displayed the most rigorous formulation effort when they described other seizure symptoms. That is, symptoms that were not subjective and that occurred beyond the bounds of reduced consciousness and/or self-control.

Unlike people with epilepsy, people with PNES have typically been shown to demonstrate sparse detailing effort and scant formulation work when they describe their attacks. Authors have reported that people with PNES tend to offer brief and condensed statements about their seizure experiences, especially in relation to periods of reduced self-control and their subjective seizure symptoms. People with PNES have typically been observed to offer limited details of their subjective seizure symptoms (if mentioned at all), and to offer short and 'holistic' descriptions of 'gaps' in consciousness (for example, *'I'm just out'*, *'that's it, I'm gone'*). Moreover, that they do not usually reformulate or elaborate on these descriptions when prompted to do so (Guelich and Schoendienst, 1999; Schoendienst, 2001; Furchner, 2002 and Surmann, 2005, cited in Schwabe et al, 2008; Schwabe, Howell and Reuber, 2007; Plug and Reuber, 2009 and Plug, Sharrack and Reuber 2009a).

Presented under the banner 'seizure description by negation', authors have also reported that people with epilepsy rarely negate seizure descriptions and where negation occurs it is usually explained and 'contextualised'. In contrast, seizure description by negation has been described as 'common and absolute' in PNES patient encounters (Schwabe, Howell and Reuber, 2007; Plug, Sharrack and Reuber, 2009a and Plug and Reuber, 2009).

Schwabe, Howell and Reuber (2007) reported that people with epilepsy in their data typically contextualized their inability to describe (recollect or report what others had told them about) what had happened during seizure episodes. For example, *'I can remember this, but I can't recall that'*. The authors termed these displays 'contextualised negations'. 'Contextualised negations' are distinct from interactive displays where people contour 'gaps' in consciousness. Schwabe, Howell and Reuber (2007) have described that 'contextualised negation' refers to an inability to describe a particular seizure manifestation that is entrenched in a description of other seizure experiences that the patient is aware of. For example, *'I know I lost consciousness, but I don't know if my eyes were open or closed while I was out'*.

In comparison, the authors found that people with PNES tended to use 'absolute negations' when they described their seizure experiences (for example, *'I feel nothing', 'I do not know anything has happened'*). 'Absolute negations' have been characterised as seizure descriptions that denote what experiences are not like, and described in terms of what the patient did not feel or remember. Akin to 'holistic' descriptions of 'gaps' in consciousness, these descriptions highlight the fact that patients may not be aware of what has occurred during seizure episodes. However, unlike the label 'holistic' (that is applied in relation to 'gaps' in consciousness), 'absolute negation' is applied to descriptions where an inability to remember (or communicate details of) a seizure experience is demonstrated. In this sense, patients do not deny that seizures occur, but they do deny the ability to remember what has happened during these episodes (Guelich and Schoendienst, 1999; Schoendienst, 2001; Furchner, 2002 and Surmann, 2005, cited in Schwabe et al, 2008; Schwabe, Howell and Reuber, 2007; Plug and Reuber, 2009 and Plug, Sharrack and Reuber 2009a).

Interestingly, Schwabe et al (2008) and Schwabe, Howell and Reuber (2007) have observed that patients with PNES may demonstrate more formulation effort describing what a seizure is not like, rather on features that characterise what a seizure is like. In addition, that the tendency of people with PNES to treat 'gaps' in consciousness as synonymous with the seizure experience often correlated with displays of 'absolute negations' of seizure experiences in their data.

A number of DSA items in the multi-rater study undertaken by Reuber et al (2009) assessed the extent to which patients used formulation effort when they described their attacks.

Item 12 of the DSA ('Formulation effort associated with description of subjective seizure symptoms') asked raters to assess the extent that participants displayed active formulation effort when they described subjective seizure symptoms. The authors defined formulation effort as including metadiscursive comments that demonstrate the difficulty of the descriptive task, the use of hesitations, reformulations, restarts and other 'self-repair' strategies and 'understanding checks' directed at the interviewer. Patients were rated as having epilepsy if they described subjective seizure symptoms with marked formulation effort. If patients demonstrated some or little formulation effort when describing subjective seizure symptoms a nil (neutral) score was applied. Patients that only offered brief subjective seizure symptom statements that were not elaborated upon, and that were characterised by little or no reformulation effort, were rated as having PNES. Using these criteria, the item proved to be significant for correct classification for one rater ($p < 0.011$).

Item 14 of the DSA ('Formulation effort associated with description of 'gaps') asked raters to assess the extent that patients displayed formulation effort when they described phases of reduced consciousness and self-control ('gaps'). Patients were rated as having epilepsy if they described these periods and/or contoured 'gaps' in consciousness with marked (a high degree of) formulation effort. A nil (neutral) score was applied if patients demonstrated some or little formulation effort when they described these periods. Patients were rated as having PNES if they did not offer any description of phases of reduced consciousness and self-control ('gaps') beyond 'holistic' statements. However,

this item did not prove significant for correct classification for either rater in the study.

For item 13 of the DSA ('Negations in descriptions of seizure experience'), raters were asked to assess the extent to which patients negated seizure experience descriptions using 'contextualised' or 'absolute negations'. Patients were rated as having epilepsy if they only used 'contextualised negations' when describing their seizure experiences. If patients used some 'absolute negations' when they described their seizure experiences a nil (neutral) score was applied. Patients were rated as having PNES if they frequently used 'absolute negations' without elaboration. However, this item did not prove significant for correct classification for either rater in the study.

3.6 Seizure metaphors

The metaphorical conceptualizations used to describe seizure episodes was a core area of scrutiny in the German data. Surmann (2005, cited in Schwabe et al, 2008) observed that the metaphorical concepts used by people with epilepsy to describe their experiences typically denoted seizures as an external threat or enemy, that approached from the outside, that acted independently of the patient's will, and that the patient described actively fighting against (metaphors were used that described a 'fight' or 'struggle'). People with epilepsy also tended to use specific and coherent metaphorical concepts throughout their seizure descriptions. Conversely, no equivalent comparisons were made to the seizure descriptions of participants with PNES, whose accounts were characterised by incoherent metaphorical conceptualisations.

A subsequent study undertaken by Plug, Sharrack and Reuber (2009b) explored the differential potential of the metaphorical conceptualization of seizures in more detail. Patients with epilepsy (n=8) or PNES (n=13) were admitted for video-EEG monitoring and interviewed by a neurologist using the 'EpiLing' interview method. A linguist blinded to diagnosis analysed transcripts of the encounters, and identified and categorized the seizure metaphors used by participants to describe their seizure experiences. No significant differences in the mean type or token count of seizure metaphors used by people with epilepsy or PNES were found. However, participants with epilepsy tended to view seizures as an independent entity. That is, patients with epilepsy typically

framed seizures as unwillingly experienced, and as actively 'struggling' or 'fighting' against seizures. Conversely, patients with PNES were more likely to describe seizures as a space or place that they entered, travelled through or came out of as 'acting agents'. The authors found that people with epilepsy tended to use metaphors that denoted seizures as an agent/force (external entity) or event/situation ('an experience located in time'), whereas people with PNES were more likely to use space/place (movements to and from different 'locations' or 'states') metaphors to describe their seizure experiences. What is more, this differential result proved statistically significant ($p=0.009$ and $p=0.039$ respectively).

The hypothesis that people with epilepsy and PNES use different metaphorical conceptualisations to describe their seizure experiences is supported (at least in part) by findings from Reuber et al's (2009) multi-rater study.

Item 15 of the DSA ('Metaphoric seizure conceptualisation') asked raters to assess the extent to which patients used consistent metaphoric conceptualisations when they described their seizure experiences. Patients were assessed as having epilepsy if their metaphoric conceptualisations of seizures (as threatening entities that acted independent of their will) were consistent across their seizure descriptions. A nil (neutral) score was applied if variations in the consistency of metaphoric conceptualisations were observed. If consistent metaphoric conceptualisation across seizure descriptions was not demonstrated, patients were rated as having PNES. The item proved significant for correct classification for both raters in the study ($p=0.009$ and $p<0.001$).

For item 16 of the DSA ('External / internal conceptualisation of seizures'), raters were asked to assess the extent to which patients conceptualised seizures as an external and/or threatening entity. If patients consistently conceptualised seizures as an external and/or threatening entity they were rated as having epilepsy. If patients sometimes (but not consistently) conceptualised seizures as an external and/or threatening entity a nil (neutral) score was applied. Patients were rated as having PNES if they did not consistently (rarely, if ever) conceptualise seizures as an external and/or threatening entity. This item also proved significant for correct classification for both raters in the study ($p=0.002$ and $p=0.03$).

Finally, item 17 of the DSA ('Conceptualisation of seizures as a fight / struggle') asked raters to assess the extent to which patients conceptualised seizures as a fight or struggle. Patients were rated as having epilepsy if they repeatedly conceptualised seizures as a fight or struggle (they used metaphors that denoted fighting or struggling with an external seizure entity). If patients sometimes conceptualised seizures as a fight or struggle a nil (neutral) score was applied. Patients were rated as having PNES if they did not conceptualise seizures as a fight or struggle. However, neither rater found this item significant for correct classification.

In addition, the findings of Thompson et al (2009) somewhat challenge those that suggest people with PNES present themselves as 'acting agents'. Using verbatim transcripts of eight semi-structured interviews with participants that had received a diagnosis of PNES in the previous six months, the authors described the language used by participants as suggesting, *"they felt overpowered by the seizures and that they remained passive and helpless throughout. For many, the helplessness was also about feeling trapped by the seizures"* (p509).

Recent exploration of the metaphoric conceptualisations used by people with seizures to describe their experiences have helped to substantiate some of the findings discussed previously. In a study of 21 initial clinical encounters (as described in Plug, Sharrack and Reuber, 2009a), Plug, Sharrack and Reuber (2011) sought to determine the range of metaphorical expressions that patients used to describe their seizure experiences and to establish if these could be related to conventional metaphors used by healthy individuals. Using finer-grain distinctions between subgroups of metaphorical tokens, three main types emerged: spatial metaphors, metaphors involving an external agent, and technological metaphors (only used by a minority of participants these suggest that the seizure episode (or part of the episode) was experienced as a mechanical or automated process). Results of the study were consistent with previous findings, with one exception: findings did not corroborate that PNES patients often failed to establish coherent metaphorical conceptualizations. Finally, the metaphorical expressions that seizure patients used to describe their seizure experiences were determined to be conventional metaphors used by healthy individuals.

3.7 Labelling

The differential use of seizure labels in patient descriptions of attacks has also been shown to be of significance. Plug, Sharrack and Reuber (2009c) analysed 21 initial clinical encounters (using methods, participants and data described previously, see Plug, Sharrack and Reuber, 2009a and 2011) and found that people with epilepsy and PNES used different labels to describe their seizures. The authors found that people with epilepsy were significantly more likely to spontaneously use the term 'seizure' compared to people with PNES ($p=0.004$). In addition, that people with PNES typically demonstrated resistance to the label 'seizure', avoided the terms 'seizure' and 'attack', and used more colloquial terms such as 'fit' or 'blackout' to describe their 'episodes'. The authors found that people with epilepsy were not overly resistant to the 'seizure' label and were more likely to adopt epilepsy specific terminology compared to the participants with PNES.

Interestingly, two studies that have explored the experiences of people with PNES concluded that the participants were often left without a definitive label to attach to their condition, and as a consequence were often unclear about the illness and its cause (Green et al, 2004 and Thompson et al, 2009).

3.8 Emotional displays

Findings from the literature suggest that people with epilepsy and PNES may express different emotions when recounting their seizure experiences and differ in their ability to acknowledge emotional factors as possible cause (or trigger) of their seizures.

In a review of the PNES literature, Reuber (2008) suggested that people with PNES were less likely to sanction emotional factors as a possible cause of seizures when they talked to doctors about their attacks. Similarly, research findings suggest that people with epilepsy are more likely to engage with emotional as opposed to physical topics when they describe their seizure experiences. For example, Ansel et al (2006) compared written accounts of seizure descriptions by people with epilepsy ($n=28$) and PNES ($n=28$) and found that the odds of being diagnosed with epilepsy (as opposed to PNES) were five times greater if the participant wrote solely about emotional topics.

However, in their 'earthquake experience' research, Watson et al (2002) found that people with epilepsy were more likely to describe seizures as physical events and that PNES participants were more likely to view seizures in emotional terms. This conclusion was based on the observation that more participants with epilepsy likened the shaking experienced during the earthquake with a seizure, whereas PNES participants were more likely to associate both the earthquake and seizure experiences with 'the feeling of losing control' and a 'sense of fear'. Similarly, in their study of PNES patients (n=8), Thompson et al (2009) found that people with PNES likened seizures to 'an altered state of consciousness', perceived seizures strange and unreal, and all participants considered seizures to have a negative emotional impact.

Finally, Gilliam et al (2009) conducted a linguistic analysis of 'naturally occurring interactions' centred on discussions of side effects between patients with epilepsy (n=60), accompanying persons (in 19 cases) and community-based neurologists (n=20). The interactions were audio and video recorded and participants and neurologists were interviewed separately post visit. Transcripts were analysed using socio-linguistic techniques derived from conversation and discourse analysis. Gilliam et al (2009) found that neurologists initiated most of the discussions regarding (negative) side effects in the interactions, and that in most instances patients denied being affected by the side effects inquired about, a discrepancy highlighted by the results of post visit interviews.

3.9 Coping styles

Although not extensively explored in a clinical research setting, Plug, Sharrack and Reuber (2009a) observed that people with epilepsy were more likely to describe actively engaging in methods to minimize the impact of seizures on their lives and report that they coped well in comparison to participants with PNES.

Thompson et al (2009) found that loss, doubt and uncertainty were common themes of PNES experiences, and PNES participants commonly cited the loss of control during a seizure, a loss of independence and a sense of isolation as salient features of their experiences. Of these characteristics, doubt and uncertainty featured prominently, this included doubt of others by the patient

(including of medical care professionals), doubt of the patient by others, and patient self-doubt. In addition, the research concluded that participants with PNES had a greater inclination than people with epilepsy to deny non-health life stresses.

In contrast, people with epilepsy have been observed to display positive coping strategies. In a study exploring the coping styles of people with epilepsy, Reuber and Monzoni (2009) found that participants presented themselves as resourceful individuals, who coped well, were 'in control', and aimed to lead as normal a life as possible. The authors concluded that the majority of participants in their data acknowledged the seriousness of their condition while presenting themselves as resourceful and optimistic individuals. They also found, however, that analysis of the interactional and linguistic features used to describe their experiences suggested that some of the participants found the condition difficult to deal with, despite their apparent 'optimism'. That is, the participants described issues in contrast to the apparently positive coping style they displayed.

"Samantha, for instance, displays topical, interactional, and linguistic features indicating that she is in control of the seizures and explicitly discusses how little the seizures interfere with her life. Then, in stark contrast with her previous 'talk', she declares: ".hh if someone could sort of .h (0.75) gi'give me umm (.) an indi- cation that by having a hysterectomy or something and getting rid of my ovaries or something .h I'd indeed put myself through that" (p656).

The authors noted that one reason for this might be that participants have more conscious control over the topic of conversation, and less control over their interactional displays (Reuber and Monzoni, 2009).

Interestingly, a similar phenomenon was observed by Gilliam et al (2009), who found that neurologists initiated most of the discussions regarding (negative) side effects during follow-up community based visits with epilepsy patients. In most instances, patients denied being affected by the side effects inquired about. However, the results of post visit interviews suggested that this was not the case, and there were discrepancies between side effect accounts and patient experiences.

Finally, findings from the German data have suggested that spontaneous reference to attempted seizure suppression may have diagnostic differential potential. Patients with epilepsy were found to offer more spontaneous accounts of seizure suppression attempts, whereas patients with PNES rarely (if ever) did so (Guelich and Schoendienst, 1999; Schoendienst, 2001; Furchner, 2002 and Surmann, 2005, cited in Schwabe et al, 2008). Schwabe, Howell and Reuber (2007) also found the use of suppression strategies to be diagnostically pertinent. In the same vein, Reuber and Monzoni (2009) concluded that people with epilepsy in their data displayed positive coping styles by capably reacting to seizures and attempting to suppress, stop or interrupt them. However, as discussed, this feature (DSA item 3 'Descriptions of attempts at seizure suppression') did not prove significant for either rater in the multi-rater study undertaken by Reuber et al (2009).

3.10 Third party witnesses

Findings from the German data suggest that references to seizure witnesses (third parties) may be a diagnostically differential feature of descriptions of phases of reduced self-control ('gaps'). The authors observed that when striving to inter-subjectively describe phases of reduced self-control, people with epilepsy sometimes resorted to reporting what witnesses had told them in order to reconstruct their experiences and 'contour' gaps in consciousness. In comparison, the authors observed that even when other people had witnessed a seizure episode, people with PNES rarely volunteered witness accounts when they described these phases (Guelich and Schoendienst, 1999; Schoendienst, 2001; Furchner, 2002 and Surmann, 2005, cited in Schwabe et al, 2008).

Schwabe, Howell and Reuber (2007) report similar results from their English-speaking population data. In addition, findings from Plug, Sharrack and Reuber's (2009a) case comparison analysis support the premise that people with epilepsy often add additional information from witness accounts to their own recollections of seizure episodes when discussing periods of reduced self-control ('gaps'). The authors observed that epilepsy patients appeared more able to provide coherent seizure trajectories based on their own memories or those of witnesses, compared to the patient with PNES.

However, according to both studies (Schwabe, Howell and Reuber, 2007; and Plug, Sharrack and Reuber, 2009a), PNES patients also referred to witness reports when they discussed their seizure episodes. However, these references were usually found to be associated with the situational and dramatic circumstances of patients' seizure episodes. In light of this, the authors concluded that both patients with PNES and epilepsy may draw on witness accounts when they describe their seizure experiences (particularly 'gaps' in consciousness). However, that people with epilepsy tend to use these references to bolster subjective accounts, whereas people with PNES do not, and may use third party references to highlight the situational and dramatic circumstances of their seizure episodes.

In order to marry these findings, two DSA items in Reuber and colleagues (2009) multi-rater study asked raters to assess the extent to which patients attempted to contour 'gaps' in consciousness using their own recollections on the one hand, or witness accounts on the other. To recount, item 10 advised raters that patients that made considerable attempts to contour 'gaps' based on their own recollections were more likely to have epilepsy and patients that relied solely on witness accounts to do this were more likely to have PNES. This item proved significant for correct classification for both raters in the study. However, when asked to assess the reconstruction of 'gaps' for individual seizure episodes using the same criteria (item 11), neither rater scored significantly.

In a study of epilepsy patients, Reuber and Monzoni (2009) found that people with epilepsy often supported factual accounts of seizure episodes with witness accounts and reported speech or thought. People with epilepsy were also found to reference family, friends or members of social networks to bolster narratives of positive coping styles:

"In some of these narratives, the introduction of a third person can appear quite defensive, as if a witness was indeed needed to support the point made by the people with epilepsy. For instance, Sandra states that her family does not even notice the seizures any longer and act as if "it's not happening." Narratives of this type reinforce the idea that the people with epilepsy has managed to integrate epilepsy into his or her life and show that the disorder is not particularly disruptive, even in the judgement of others" (p654).

The authors also observed that some people with epilepsy normalised their experiences by citing third parties with more severe epilepsy as a means to contrast their current situation and perceive it as more favourable (Reuber and Monzoni, 2009).

Third party and seizure witness references also featured in other literature identified for inclusion in the review. Watson et al (2002) found that many participants in their study (both with epilepsy and PNES) reported they only knew shaking occurred during their seizures through witness accounts. In addition, Thompson et al (2009) reported that the doubt and uncertainty expressed by people with PNES included doubt of others by the patient (including healthcare professionals) and doubt of the patient by others. Similarly, Plug, Sharrack and Reuber (2009c) observed that patients with PNES were more likely to express dissatisfaction with previous treatment (and healthcare professionals) compared to patients with epilepsy.

4. Discussion

Analysis of the research findings presented in this review suggest that previously identified interactional, linguistic and topical features of seizure patient talk can be thematically classified as falling into two broad categories, 'interactive resistance' and 'subjective capacity'. A discussion of these concepts is presented below. Following this, the differential potential of third party references is discussed in light of these concepts.

4.1 Interactive resistance

Characterised by avoidance and a lack of focus, 'interactive resistance' can be considered juxtaposed to displays of engagement and initiation. The extent to which people with seizures demonstrate 'interactive resistance' appears to be central to many (if not most) of the differential features of seizure patient talk described in this review.

At a baseline level, findings suggest that people with epilepsy usually initiate seizures as a topic of discussion and volunteer descriptions of their seizure experiences. In contrast, patients with PNES have been shown to avoid offering

these descriptions (Guelich and Schoendienst, 1999; Schoendienst, 2001; Furchner, 2002 and Surmann, 2005, cited in Schwabe et al, 2008; Schwabe, Howell and Reuber, 2007; Plug and Reuber, 2009 and Plug, Sharrack and Reuber 2009a). These differential findings are reflected in study that took place in a setting and context far removed from that of a doctor's office. During telephone interviews in which earthquake experiences were discussed, Watson et al (2002) found that people with epilepsy were significantly more likely to initiate seizure descriptions as a topic of discussion compared to people with PNES.

Differences in 'interactive resistance' have also been described in relation to the interactive challenges patients face when they describe their attacks.

Authors have reported that people with epilepsy tend to 'contextualise' omissions in their descriptions, and imbed elements of what they do not know about their seizure experiences in descriptions of what they remember or have been told. In contrast, authors have observed that patients with PNES have a greater tendency to use 'absolute negations' when they describe their seizure experiences. That is, they demonstrate an inability to remember or communicate details of their seizure experiences (and may discuss seizures in terms of what they are not like) (Schwabe, Howell and Reuber, 2007; Plug, Sharrack and Reuber, 2009a and Plug and Reuber, 2009).

Similarly, people with epilepsy have typically been found to elaborate on or reformulate previous descriptions of 'gaps' in consciousness when prompted to do so. Conversely, a lack of elaboration or reformulation of prior 'holistic' statements about 'gaps', often despite considerable prompting to do so, has been described as a distinguishing feature of PNES patient talk. When a high degree of interactive resistance was demonstrated in response to challenges about prior 'holistic' statements, these statements were characterised as being 'absolute and beyond challenge'. The differential interactive behaviours described here have also been observed in relation to patients' descriptions of their subjective seizure symptoms (Guelich and Schoendienst, 1999; Schoendienst, 2001; Furchner, 2002 and Surmann, 2005, cited in Schwabe et al, 2008; Schwabe, Howell and Reuber, 2007; Plug and Reuber, 2009 and Plug, Sharrack and Reuber 2009a).

Aligned with avoidance tendencies, a distinguishing feature of 'interactive resistance' is 'focusing resistance'. Authors have reported that people with epilepsy are easily able to focus on seizure descriptions, and provide detailed, coherent accounts of individual seizure episodes and trajectories. What is more, that these accounts typically include displays of 'contouring' 'gaps' in consciousness, reports of subjective seizure symptoms, descriptions of the different grades of consciousness experienced, and 'gaps' are presented as just one of several elements of seizure episodes. In comparison, authors have reported that people with PNES usually display considerable difficulty focusing on seizure episodes, typically offer brief ('holistic') statements about their seizure experiences that lack detail, equate 'gaps' in consciousness as synonymous with the overall experience, and avoid discussing subjective seizure symptoms. It is not surprising then that people with PNES have typically been observed to provide accounts of their seizures (trajectories) that are difficult to understand (Guelich and Schoendienst, 1999; Schoendienst, 2001; Furchner, 2002 and Surmann, 2005, cited in Schwabe et al, 2008; Watson et al, 2002; Schwabe, Howell and Reuber, 2007; Plug and Reuber, 2009; Plug, Sharrack and Reuber 2009a).

These findings are echoed in studies that have explored groups of patients with either epilepsy or PNES. A study of epilepsy participants corroborated findings that suggest people with epilepsy typically initiate seizures as a topic of discussion, provide coherent seizure trajectories, and offer detailed accounts of their experiences without prompting from the doctor (Reuber and Monzoni, 2009). Studies that have examined the experiences of people with PNES have observed that they typically found it difficult to coherently describe the trajectory of their condition and were often confused about their experiences and the timeline of their illness (Lacey, Cook and Salzberg, 2007; Thompson et al, 2009 and Green et al, 2004).

In addition, items quantitatively assessing the extent to which patients initiate and are able to focus on seizure experiences proved significant for correct classification for at least one rater across no less than six DSA items in a multi-rater study (Reuber et al, 2009). One rater found item 1, ('General focus on seizure experience'), item 2 ('Description of subjective seizure symptoms'), item 4 ('Description of phases of reduced self-control') and item 6 ('Description of individual seizure episodes') significant for correct classification. In addition,

item 9 of the DSA ('Relative importance of 'gaps') proved significant for correct classification for both raters. Finally, individual seizure trajectory coherence formed a cornerstone of the criteria for DSA item 10 ('Contouring of 'gaps' in individual seizure episodes'). This item also proved significant for both raters for correct classification in the study.

Interactive and focusing resistance is also important when considering another distinguishing feature of seizure patient talk, formulation effort.

Qualitative studies have consistently pointed to formulation effort as a distinguishing feature of patients' descriptions of their attacks. Authors have reported that people with epilepsy typically take care describing and detailing their experiences, and use extensive formulation to do this. In contrast, people with PNES have been observed to offer short statements that lack detail, and the formulation effort used to communicate their experiences is less evident (Guelich and Schoendienst, 1999; Schoendienst, 2001; Furchner, 2002 and Surmann, 2005, cited in Schwabe et al, 2008; Watson et al, 2002; Schwabe, Howell and Reuber, 2007; Plug and Reuber, 2009 and Plug, Sharrack and Reuber, 2009a).

Findings from the wider literature appear to support the finding that people with epilepsy typically demonstrate more formulation effort than people with PNES when they discuss their attacks. Prigatano and Kirlin (2009) explored the cognitive functioning of epileptic (n=22) and PNES patients (n=23) and found that people with PNES reported greater word-finding difficulty than people with epilepsy (p0.02). However, people with PNES performed better than people with epilepsy on the Boston Naming Test (p0.03), suggesting that PNES patients overestimated word-finding difficulty. This may help explain why, and/or add credence to the observation that patients with PNES have been observed to resist attempts at active formulation work when discussing their seizure experiences.

However, it is notable that most of the DSA items that asked raters to assess formulation effort in a multi-rater study (Reuber et al, 2009) did not prove significant for correct classification, for either rater. These included, item 5 ('Response to challenge of statements about 'gaps)'), item 13 ('Negations in descriptions of seizure experience') and item 14 ('Formulation effort' associated

with description of 'gaps'). The only DSA item that asked raters to assess formulation effort that proved to be significant for correct classification was item 12 ('Formulation effort associated with description of subjective seizure symptoms'). However, it is notable that rigid criteria were applied to the analysis of formulation effort in the DSA, much of which was centred on descriptions of periods of reduced self-control, and comparators were used (for example, those relating to 'nil' or 'neutral' scores) that had not been explored in previous qualitative research. It may be the case that further qualitative work, and quantitative testing, is required before formulation effort can be optimised as a distinguishing feature of seizure patient talk in a DSA.

The reasons why people with epilepsy and PNES appear to differ in their abilities or willingness to initiate and focus on seizure descriptions cannot be attributed to any particular psychological disposition. The findings presented here merely appear to suggest that people with PNES tend to be less able or willing to communicate details of their seizure experiences compared to people with epilepsy. However, it is notable that dissociation and avoidance behaviours are key psychopathological features of PNES (Frances, Baker and Appleton, 1999; Reuber et al, 2007; Griffith, Polles and Griffith, 1998 and Goldstein et al, 2000). In addition, that PNES is usually interpreted as a manifestation of dissociative avoidance behaviour triggered by emotional arousal (Reuber, 2009 and Goldstein and Mellers, 2006). Therefore, the 'interactive resistance' typically displayed by people with PNES (avoiding and resisting detailed (and subjective) discussions of seizure experiences, often despite considerable prompting to do so) may reflect the underlying psychopathology of the condition.

4.2 Subjective capacity

The term 'subjective capacity' encapsulates many of the features of seizure patient talk described in this literature review. For example, the ways in which patients communicate their own, internal, recollections of seizure events (subjective seizure symptoms), the metaphors used to describe attacks (metaphorical conceptualisations), the emotions patients display when they describe their seizure experiences (emotional displays), and how patients describe coping with their experiences (coping skills).

The inclusion and use of subjective seizure symptoms has been shown to be a distinguishing feature of seizure patient talk across many of the studies identified for inclusion in the review.

Qualitative findings have shown that people with epilepsy tend to volunteer subjective seizure symptoms, take care detailing these, and that descriptions of these symptoms are central to their accounts. In addition, people with epilepsy have typically been found to reformulate or elaborate on subjective seizure symptom descriptions when prompted to do so. In comparison, participants with PNES have been shown more likely to offer brief ('holistic') seizure 'statements' that are devoid of subjective seizure symptom descriptions. People with PNES have been also been observed to avoid discussing or elaborating on subjective seizure symptoms, often despite considerable prompting to do so (Guelich and Schoendienst, 1999; Schoendienst, 2001; Furchner, 2002 and Surmann, 2005, cited in Schwabe et al, 2008; Schwabe, Howell, and Reuber, 2007; Plug and Reuber, 2009; Reuber et al, 2009; and Plug, Sharrack and Reuber, 2009a).

The differential use of subjective seizure symptoms also proved significant for correct classification across several items in the multi-rater study conducted by Reuber et al (2009). For example, item 2 (initiation of 'Descriptions of subjective seizure symptoms'), item 7 (level of detail attached to 'Subjective seizure symptoms' accounts), and item 12 ('Formulation effort' associated with description of subjective seizure symptoms') all proved significant for correct classification for one rater. In addition, in DSA item 1 ('General focus on seizure experience'), subjective symptoms were integral to the assessment of 'seizure experiences', and in item 6 ('Description of individual seizure episodes'), 'description' referred to accounts that incorporated subjective seizure symptoms. One rater found both of these items significant for correct classification. Moreover, item 8 of the DSA ('Relative importance of subjective seizure symptoms') proved significant for correct classification for both raters in the study.

Findings that describe the different ways seizure patients use metaphors to conceptualise their experiences (what they liken seizures to) are also encompassed under the banner 'subjective capacity'.

In the German data, it was observed that people with epilepsy typically conceptualised seizures as independent entities that they described actively 'fighting' or 'struggling' against. However, the researchers reported that no consistent metaphorical conceptualisations could be identified in PNES patient descriptions of their attacks (Surmann, 2005, cited in Schwabe et al, 2008). Building on this work, Plug, Sharrack and Reuber (2009b and 2011) used finer-grained distinctions to differentiate between the metaphors used by people with epilepsy and PNES. The authors found that people with epilepsy tended to conceptualise seizures as an external agents/forces or events/situations that were unwillingly experienced. In addition, that people with epilepsy often described 'fighting' with or 'struggling' against seizures, whereas people with PNES rarely (if ever) did so (Plug, Sharrack and Reuber, 2009b and 2011). Finally, in contrast to previous findings, the authors observed that there was consistency in the metaphorical conceptualisations used by PNES participants to describe attacks in their data. They found that PNES patients typically used metaphors that conceptualised seizures as spaces/places they entered as 'acting agents' (Plug, Sharrack and Reuber 2009b and 2011).

In addition, two of the three DSA items that asked raters to assess metaphoric conceptualisations of seizures proved significant for correct classification in a multi-rater study (Reuber et al, 2009). Item 17 of the DSA ('Conceptualisation of seizures as a fight / struggle') did not prove significant for either rater. However, DSA items 15 ('Metaphoric seizure conceptualisation') and 16 ('External / internal conceptualisation of seizures') proved significant for correct classification for both raters in the study.

Nevertheless, the differential use of metaphoric conceptualisations appears to be contested in part by other findings from the review. People with PNES have been shown to liken seizures to 'an altered state of consciousness', to describe seizures as 'strange' and 'unreal', and that they report feeling 'passive, trapped and overwhelmed' by attacks (Thompson et al, 2009). People with PNES have also been observed to describe seizures as 'confusing' and 'beyond their control' (Green et al, 2004). These findings appear to indicate that (at least) some people with PNES conceptualise seizures as external entities or forces over which they have little, if any, control, and that are unwillingly (albeit 'passively') experienced. It may be the case that the metaphorical

conceptualisations used by PNES patients when they describe their attacks do not reflect how they experience seizure episodes.

Within the concept of 'subjective capacity', the communication of emotion appears to be of particular importance. This includes the literal expression of emotion (for example, as featuring in descriptions of subjective seizure symptoms and coping strategies) and figurative emotional expressions (for example, metaphoric conceptualisations of seizure experiences) (Fussel, 2006).

Findings from the review suggest that people with epilepsy and PNES differ in their ability to express emotion when they describe their seizure experiences. Ansel et al (2006) observed that people with epilepsy in their data were much more likely to engage with emotional topics in comparison to physical 'sequelae'. However, as highlighted in the results section of this review, there is some contention in the literature. For example, Watson et al (2002) observed that people with epilepsy were more likely to discuss seizures in physical rather than emotional terms. However, this conclusion was based on the observation that people with PNES were more likely to associate both seizures and the earthquake experience with a sense of 'losing control' and 'fear', whereas people with epilepsy were more likely to associate the earthquake experience with a seizure (physical event). The key here then appears to be to differentiate between the emotions expressed, and whether these are negatively orientated, or not.

In the absence of subjective seizure symptoms, authors have observed that people with PNES tend to dramatise events (Schwabe et al, 2008; Schwabe, Howell and Reuber, 2007), orientate discussions around the circumstances or consequences of seizures (Plug, Sharrack and Reuber, 2009a) and/or focus on other (negative) aspects of their experiences (Plug and Reuber, 2009). Similarly, Thompson et al (2009) observed that people with PNES commonly cited feelings of doubt, loss and uncertainty when they described their seizure experiences.

The finding that people with PNES frequently reference 'negative' emotions when they describe their seizure experiences is reflected in studies that have explored the coping styles of people with seizures. As Reuber et al (2005) have pointed out, PNES are not only a response to psychological distress, but also

signify a failure to adopt alternative (positive) coping mechanisms. People with PNES have been observed to engage in avoidant (maladaptive) coping behaviours (Frances, Baker and Appleton, 1999), especially in comparison to people with epilepsy (Stone, Binzer and Sharpe, 2004).

In linguistic studies, people with PNES have been observed to have a greater tendency to discuss the (negative) impact of seizures on their lives compared to people with epilepsy (Plug, Sharrack and Reuber, 2009c and Plug and Reuber, 2009). In addition, Thompson et al (2009) observed that all of the PNES participants in their study described seizures as having a negative emotional impact on their lives.

In comparison, people with epilepsy have been observed to describe actively minimising the impact of the condition on their lives and to engage in positive coping strategies (Plug, Sharrack and Reuber, 2009a and Reuber and Monzoni, 2009), to the extent that they have been observed to 'over normalise' their experiences (Reuber and Monzoni, 2009). In addition, research findings suggest that when confronted with negative subject matter (such as 'side effects') patients with epilepsy may resist initiating discussions and deny negative consequences (Gilliam et al, 2009). Moreover, that when faced with the choice of discussing seizures in physical or negatively emotional terms, patients with epilepsy may resort to discussing the physical aspects of seizure experiences, as appears to be the case in Watson et al's (2002) study.

In summary, these findings suggest that 'subjective capacity' underlies many of the differential features identified in the literature. Although patients with PNES may have a tendency to deny psychological factors, negative life events and their emotional consequences as contributing to their seizure condition (Stone, Binzer and Sharpe, 2004; Reuber, 2008 and Thompson et al, 2009), it appears that patients with PNES have a tendency to orientate towards the 'negative' when discussing their seizure experiences (particularly in the absence of subjective seizure symptoms and when describing coping strategies), whereas people with epilepsy do not (and may even 'over normalise' their experiences).

4.3 Third party references

'EpiLing' project researchers have reported that people with epilepsy may resort to adding seizure witness (third party) accounts to descriptions of periods of reduced consciousness in an attempt to piece together what has happened during these episodes, whereas, even if available, people with PNES do not ordinarily volunteer these (Guelich and Schoendienst, 1999; Schoendienst, 2001; Furchner, 2002 and Surmann, 2005, cited in Schwabe et al, 2008).

However, other research findings paint a different picture. For example, Watson et al (2002) reported that many participants (with epilepsy and PNES) in their study only knew shaking had occurred during seizures episodes through witness accounts. Similarly, UK authors have observed that both people with epilepsy and PNES refer to third parties or seizure witnesses when describing their attacks. However, that the differential use of these third party references may be diagnostically significant (Schwabe, Howell and Reuber, 2007; Plug and Reuber, 2009 and Plug, Sharrack and Reuber 2009a).

People with epilepsy have typically been observed to reference third parties and seizure witnesses to bolster their own recollections of seizure experiences (Schwabe, Howell and Reuber, 2007 and Plug, Sharrack and Reuber, 2009a). In contrast, people with PNES have been observed to use third party references to orientate discussions around the circumstances and (dramatic) consequences of seizure episodes (Schwabe, Howell and Reuber, 2007 and Plug, Sharrack and Reuber, 2009a).

The observation that people with epilepsy use third party references to retain a focus on the 'internal' (bolstering their own recollections), whereas people with PNES use these references to focus on the 'external' (to direct discussion to the situational and circumstantial) appears to be substantiated by studies in the wider literature. For instance, Stone, Binzer and Sharpe (2004) found that people with PNES have a (significantly) greater external locus of control compared to people with epilepsy.

The differential use of third party references was tested to a limited extent in Reuber et al's (2009) a multi-rater study. For items 10 ('Contouring of 'gaps' in seizure trajectory') and 11 ('Reconstruction of 'gaps'') of the DSA, raters were

asked to assess the extent to which patients contoured periods of reduced consciousness or self-control using their own recollections on the one hand, or witness accounts on the other. In the study, item 10 of the DSA proved significant for correct diagnosis for both raters. However, item 11 did not prove significant for correct classification for either rater. It may be the case that the comparator of 'own recollections' does not help distinguish between how patients with epilepsy and PNES use third party references when reconstructing what has happened during periods of reduced consciousness and unconsciousness. A wider perspective may need to be taken.

Looking at the use of third party references from a different viewpoint, it appears that the different emotions expressed by people when they use third party references to describe what has happened during attacks, how they cope with the disorder, and the impact the condition has on their lives, may have differential potential.

Findings from the literature review suggest that people with epilepsy may use third party references in more 'positive' contexts than people with PNES. Reuber and Monzoni (2009) reported that people with epilepsy in their study tended to 'over normalise' their experiences, and enhanced accounts of positive coping strategies by referencing others, including those they perceived as worse off than themselves. In comparison, people with PNES have been observed to use third party references to express doubt and uncertainty of others (third parties) and to convey how they are doubted by others (including healthcare professionals) (Thompson et al, 2009). Similarly, Plug, Sharrack and Reuber (2009c) observed that people with PNES were more likely to discuss dissatisfaction with previous treatment (with reference made to healthcare professionals) compared to people with epilepsy.

In addition, the literature included in this review suggests that people with PNES may reference third parties 'negatively' in the sense of being socially dependent on others. A loss of independence and a sense of isolation featured as salient factors in Thompson's et al's (2009) study of PNES patient accounts.

In addition, Reuber (2008) suggested that in chronic PNES cases, social and/or financial illness gain may feature as a rewarding element of seizure episode or seizure condition 'dramatisation', and in extreme cases patients may achieve or

maintain a 'sick role' and pass on unpleasant responsibilities to others. In this respect, it is interesting to note that research has indicated that 'third parties' (for example, family, friends or co-workers) may reinforce a PNES patient's adverse behaviours (Lesser, 2003). That is, people the patient knows may help to create and/or sustain a cycle of dependency, and their actions may contribute to or help maintain maladaptive coping strategies.

These findings are interesting as there is a well-established body of research that suggests that family dysfunction, trauma and abuse are significantly greater in PNES populations compared to epileptic populations and 'healthy' control groups (Griffith, Polles and Griffith, 1998; Krawetz et al, 2001 and Alper et al, 1993). Indeed, there is considerable evidence to suggest that abusive or traumatic events or dysfunctional environments may lead to the development of the disorder (Benbadis, 2005). What is more, insecure (adult) attachment has been established as a long-term consequence of trauma and abuse among people with PNES (Holman et al, 2008).

5. Limitations

This review is limited in a number of respects. The review only included papers written in or translated to the English language. There are some significant pieces of literature written in the German language that are absent from this review. Summaries of these papers are presented in an English language article (Schwabe et al, 2008) and findings have been included as appropriate, nevertheless, the original publications were not assessed. In addition, only studies published after 1989 were included. No relevant literature published before this date was identified during the scoping exercise, however, it could be the case that applicable literature published before this date is absent from this review.

As described in the methodology section, studies were not included in the review if they exclusively explored epilepsy or PNES in the context of a co-morbid serious psychological illness, chronic physical disorder, significant learning disability or pre/post major neurological surgical intervention. In many ways, these constraints significantly limited the yield and range of literature to be included. As previously described, there is a high prevalence of co-morbid serious psychological illnesses, chronic physical disorders and significant

learning disabilities in seizure patient populations (Bodde et al, 2009; Reuber 2009; Gaitatzis et al, 2004 and Strine et al, 2005). However, these constraints were imposed for reasons of comparability. Studies that exclusively included these sub-groups of seizure patients do not necessarily represent 'standard' epilepsy and PNES patient populations.

It is also notable that, while some research was identified during the full search that explored the ways in which people with seizures who have significant learning disabilities, chronic physical disorders, serious psychological illnesses, or have been assessed for major neurological surgical intervention described their attacks, the 'interactional' exploration of seizure patient talk was a minor consideration in these studies.

For example, a study by Reutens and colleagues (1997) explored the results of surgical treatment in five patients with temporal lobe epilepsy with chronic psychosis. In the article the authors reported what patients had to say about their seizures. For example, one patient, "*confided that his body, brain and mind were controlled by the devil ...[].. He considered his inability to control seizures with willpower another example of his brain being controlled by the devil. His affect was inappropriate with silly laughter*" (p1930). Similarly, as described in the methodology section of this review, studies were identified that included qualitative analysis of Quality of Life (QoL) indicators. Some of this research included patient descriptions of attacks.

However, the interactional analysis of these descriptions was a marginal consideration in these types of studies, which would have been excluded on the grounds that their primary aims and objectives did not include an 'interactional' exploration of seizure patient descriptions of attacks, regardless of the types of seizure participants examined. Nevertheless, these studies may have provided additional insights into how and why people with seizures describe their experiences in the ways they do.

It is also the case that, proportionally, the review contains a substantial body of work undertaken by researchers from the 'EpiLing' project and the 'Listening to people with seizures' project. Moreover, the majority of research conducted by the 'UK team' has used the same data sources (to varying degrees) in their analyses. The same may also be true of the 'EpiLing' project data. Only five

empirical studies from the wider literature were identified for inclusion in the review (Watson et al, 2002; Green et al, 2004; Ansel et al, 2006; Thompson et al, 2009 and Gilliam et al, 2009). Of these, only two studies (Watson et al, 2002; Ansel et al, 2006) included both patients with epilepsy and PNES. This may significantly constrain the generalizability of findings from this review.

Moreover, and as previously discussed, all of the 'EpiLing' and 'Listening to people with seizures' project data described in this review were gathered using the 'EpiLing' interview method. Doctor-patient interactions have historically been described as asymmetrical (Byrne and Long, 1976 and Mishler, 1984), and although the doctor-patient relationship has been described as more egalitarian in recent decades (Tates and Meeuwesen, 2000), power imbalances still exist. In sum, the 'EpiLing' interview (history-taking) procedure is likely to be quite different from that experienced by patients in other clinical environments.

Patients that are interviewed using the 'EpiLing' method may find the doctor's use of open questions, the absence of interruptions, and the lack of direct questions disconcerting. These features could influence how patients describe their experiences. For example, patients may be unusually talkative to cope with the fact that the doctor's contributions are limited in these interactions. In addition, the pauses, hesitations, restarts and reformulations observed in seizure patient descriptions may be a consequence of 'space filling'. Given that the doctor's contributions are kept to a minimum in these encounters, it appears that patients are more likely to initiate and volunteer information than patients in other (more 'traditional') doctor-patient interactions. Patients may also find the 'challenge phase' of the interview (that takes place toward the end of the consultation) unnerving, especially after they have been given considerable time and space in which to describe their experiences (during which they were purposefully not asked to clarify or to elaborate on their descriptions).

For these reasons, data gathered using the 'EpiLing' interview method might not be representative of data gathered from 'routine' clinical practice, and this may further limit the generalizability of findings from this review.

6. Conclusion

Despite the limitations outlined above, a significant yield of literature was included in this review considering the specialised and niche area of research explored; 16 articles, including 13 empirical pieces were identified for inclusion.

Findings from 'EpiLing' and 'Listening to people with seizures' project data suggest that the extent to which patients with seizures initiate and are able to focus on descriptions of their attacks, the level of detail attached to these descriptions, the formulation effort they use, their metaphorical conceptualisations of these episodes, descriptions of their subjective symptoms, and the labels they use to describe the condition are diagnostically relevant. Within this, patient descriptions of periods of reduced consciousness and self-control, and the interactive behaviours they display while recounting these, are particularly important (Guelich and Schoendienst, 1999; Schoendienst, 2001; Furchner, 2002 and Surmann, 2005, cited in Schwabe et al, 2008; Schwabe, Howell and Reuber, 2007; Schwabe et al, 2008; Plug, Sharrack and Reuber, 2009a, 2009b, 2009c, 2011; Reuber et al, 2009 and Plug and Reuber, 2009).

In addition, empirical findings from the wider literature support previous observations that PNES and epilepsy patients display distinct communication profiles and there are diagnostically relevant linguistic, interactive and topical differences in how people with epilepsy and PNES describe their attacks (Watson et al, 2002 and Anschel et al, 2006). Similarly, studies of epilepsy or PNES patient groups appear to substantiate the findings of comparative studies (Green et al, 2004; Thompson et al, 2009; Reuber and Monzoni, 2009 and Gilliam et al, 2009).

Quantitatively, the most substantive and convincing research to test the differential potential of these features was the blind-prospective multi-rater study undertaken by Reuber et al (2009). Some discrepancies between previous qualitative findings and those found in the multi-rater study have been discussed. Nevertheless, the overall results of the multi-rater study strongly support the case that topical, linguistic and interactive differences in patients' descriptions of their attacks can help distinguish between people with epilepsy and PNES. The results of the study suggest that qualitative observations can be converted into a quantitative score to predict correct diagnosis. However, as

was discussed, some items of the DSA used in the study appear to require further qualitative work and quantitative testing to increase its diagnostic accuracy, particularly those items that include assessment of formulation effort.

Three relatively unexplored features of seizure patient talk that appear to have promising differential potential emerged from the review; 'emotional displays', 'coping skills' and 'third party references'.

Thematic analysis of the differential features described in the results section of the review revealed that many of the features identified could be classified as falling into two broad categories; 'interactive resistance' and 'subjective capacity'. What is more, that these two features, particularly that of 'subjective capacity' could provide a useful focus for exploring differences between how people with epilepsy and PNES reference others (third parties) when they describe their seizure experiences.

The theme of 'interactive resistance' emerged from the observation that many of the differential features of seizure patient talk identified in the review appeared to be defined by engagement with or avoidance of seizure experience discussions, and the ability or willingness of patients to focus on or resist discussion of these experiences. Broadly, findings from the review suggest that patients with PNES typically exhibit interactional resistance when discussing their seizure experiences, whereas people with epilepsy do not.

'Subjective capacity' emerged as a theme for discussion following the observation that people with seizures appear to express different emotions when describing their experiences and how they cope with their condition. The theme encapsulates two important features of seizure patient talk identified in the literature: 'subjective seizure symptoms' and 'metaphorical conceptualisations'. However, the theme also includes two relatively unexplored features of seizure patient talk that may have significant differential potential: 'emotional displays' and 'coping skills'.

'Emotional displays' and 'coping skills' have not been extensively explored in previous 'EpiLing' and 'Listening to people with seizures' studies. Previous findings have only hinted at the observation that people with epilepsy and PNES appear to display different emotions when they describe their attacks, when

they discuss the impact of attacks on their day-to-day lives, and how they describe coping with their seizure condition (Plug, Sharrack and Reuber, 2009a and Plug and Reuber, 2009 and Reuber and Monzoni, 2009). However, after considering the findings from other studies identified for inclusion in the review (namely, those of Watson et al, 2002; Green et al, 2004; Anshel et al, 2006; Thompson et al, 2009 and Gilliam et al, 2009), a case emerged to suggest that the differential potential of 'coping styles' and 'emotional displays' warrants further exploration.

In terms of 'emotional displays', findings from the review broadly suggest that people with PNES have been observed to express 'negative' emotions when they describe their seizure experiences (Watson et al, 2002; Anshel et al, 2006; Plug and Reuber, 2009; Plug, Sharrack and Reuber, 2009a). In comparison, people with epilepsy have typically been observed to 'normalise' their experiences and express 'positive' emotions when they describe how they cope with the condition (Reuber and Monzoni, 2009). In addition, people with epilepsy have been observed to avoid discussions of 'negative' subject matter (Gilliam et al, 2009), to the extent that they may discuss experiences in physical rather than (negative) emotional terms (Watson et al, 2002).

Similarly, findings from the review indicate that people with epilepsy tend to report positive coping styles and minimization of the impact of the condition on their lives (Plug, Sharrack and Reuber, 2009a, 2009c; Plug and Reuber, 2009 and Reuber and Monzoni, 2009). Conversely, people with PNES have been observed to describe the negative impact seizures have on their lives (Plug, Sharrack and Reuber, 2009c; Green et al, 2004 and Thompson et al, 2009).

The emotional displays described above were observed beyond the confines of subjective seizure symptom descriptions, that is, descriptions of what patients thought and how they felt *during* (and immediately before and after) seizure episodes. For example, many of the emotional displays observed in the literature were associated with the situations and circumstances in which seizures had taken place, the consequences of attacks, the impact of seizures on patients day-to-day lives, and how patients coped with their seizure condition. It is therefore suggested that future studies that explore interactive differences in how patients with epilepsy and PNES display emotions should not

be confined to seizure descriptions alone (for example, periods of reduced consciousness and self-control).

In order to help inform the next phase of study, one of the primary aims of the review was to identify research that included exploration of third party references in seizure patient accounts. However, only a small proportion of the studies identified for inclusion examined third party references in any meaningful way, and most discussed third party references as a point of interest within the scope of other research objectives.

For example, authors have reported that both people with epilepsy and PNES reference third parties when they describe their attacks. However, that people with epilepsy tend to use third party references to add to their own recollections of seizure episodes, whereas people with PNES typically reference third parties in relation to the circumstances or consequences of seizure episodes (Schwabe, Howell and Reuber, 2007 and Plug, Sharrack and Reuber, 2009a). This hypothesis was tested to a limited extent in Reuber et al's (2009) multi-rater study (as part of the criteria for items 10 and 11 of the DSA). However, criteria for these items limited raters to the assessment of individual seizure episodes and trajectory discussions, descriptions of periods of reduced self-control or consciousness, and the comparator of 'own recollections' was used.

The findings from this review suggest that when third party references are used (for example, to describe periods of reduced self-control) may not be as important, or differentially significant, as *how* these references are used. Findings suggest that people with PNES may be more likely to use third party references when they describe the circumstantial or dramatic consequences of seizure episodes, dissatisfaction with medical treatment, and social dependency. In comparison, findings suggest that people with epilepsy may be more likely to use third party references in more 'positive' contexts, for example, to bolster positive coping styles and to 'normalise' their experiences.

For example, people with epilepsy have been observed to reference third parties to validate and bolster accounts of positive coping strategies (Reuber and Monzoni, 2009). Conversely, people with PNES have been observed to use third party references to express doubt and uncertainty (Thompson et al, 2009), to express dissatisfaction with previous medical treatment (Thompson et al,

2009 and Plug, Sharrack and Reuber, 2009c), to describe the dramatic, embarrassing or potentially dangerous consequences of seizures (Schwabe, Howell and Reuber, 2007 and Plug, Sharrack and Reuber, 2009a) and to discuss social isolation and dependency (Thompson's et al, 2009 and Reuber, 2008).

In conclusion, the differential potential of third party references appears promising. The findings from this review suggest that the focus of such an analysis should be on *how* third party references are used. In particular, a focus on the 'emotional use' of third party references is suggested. Finally, it appears that seizure patients reference third parties throughout their accounts (for example, when describing previous medical treatment, coping styles, and the (social and emotional) impact of the condition on their day-to-day lives). Therefore, it is suggested that future studies that explore differences in how people with seizures reference third parties should not be limited to discussions of periods of reduced consciousness and self-control.

Findings from this review were used to inform the empirical study presented in the next chapter of this thesis, in which the distribution and use of third party references in 20 one-to-one initial seizure patient consultations were explored.

Chapter three: Distinguishing features of third party references in doctor-seizure patient encounters.

1. Introduction

The results of the literature review described in chapter two indicated that the diagnostic differential potential of third party references is an area of particular interest for further exploration. However, whilst previous work has alerted researchers (and neurologists) to the important role that references to people who are not present during consultations with seizure patients (third parties) can play, these references have not been examined or described in detail. The study presented here aimed to address this gap in knowledge by describing the frequency and differential potential of observations relating to references to third parties in 20 one-to-one seizure patient encounters, using (qualitative) content analysis methods.

The chapter begins by outlining the aims and objectives of the study. Thereafter, the context of the consultations, the procedure by which participants were recruited to the study and the clinical and demographic data collected from participants is presented. Following this, the interview method used by the doctor in the consultations to collect data is described.

Next, the analytical perspective taken to the content analysis is discussed. A discussion of how codes were developed and applied to the data is then offered. In this section, extracts from verbatim transcripts were used to highlight observations based on analysis of the data, and to demonstrate how codes were developed, refined and eventually applied to the data. Following this, the statistical methods used to analyse data are presented.

The results section of the chapter begins with a description of the clinical and demographic differences between diagnostic groups (participants with PNES and participants with epilepsy). Results of the content analysis are then presented. These results are subsequently discussed in the context of findings from the literature review (presented in chapter two) and relevant literature from the wider fields of medical, psychological and social science.

Finally, a discussion of the study's limitations is presented and concluding remarks are offered.

1.1 Aims and objectives

The primary aim of this exploratory study was to investigate differences between the frequency and use of third party references by participants with epilepsy and participants with PNES in 20 one-to-one doctor-patient consultations ('interviews') with a neurologist.

The method of analysis used in this study was content analysis. As described by Joffe and Yardley (2004), the aim of content analysis is not to undertake an in-depth analysis of the interconnections between meanings within one narrative, or a small number of narratives. The aim is to examine how thematic contents are expounded by groups of participants and to identify meaning across many participants.

One of the primary objectives in any content analysis is the development of a coding frame (Krippendorff, 1980). A main objective of code development in this analysis was to identify and analyse references to others not present (third parties) in order to develop, refine and operationalize ('third party reference') codes for use in the final coding frame. In addition, it was anticipated that sub-categories of 'third party' codes would arise from this analysis.

It was previously suggested (in chapter two) that the use of third party references in 'positively' or 'negatively' orientated patient accounts might have differential potential. Therefore, another main objective of code development was identification and thematic analysis of third party references used by patients in 'positive' or 'negative' contexts. It was hoped that these codes (and subsequent sub-categories of these codes) could be developed and refined for use in the final coding frame.

The final objective of the study was to examine differences between the frequency and use of third party references (as directed by the final coding frame) by participants with epilepsy and participants with PNES using statistical methods.

2. Methods

2.1 Participants

The 20 consultations described in this study form part of a dataset previously collected by members of the Academic Neurology at the Royal Hallamshire Hospital (Sheffield, UK) as part of the 'listening to people with seizures' project.

Between May 2005 and January 2008 unselected adults (aged over 18 years) with refractory seizures who had been referred for 48 hours of video-EEG observation to the Department of Neurology at the Royal Hallamshire Hospital by a Consultant Neurologist because of diagnostic uncertainty were invited to take part in a study.

Patients were recruited to the study by the Consultant Neurologist (MR), who also obtained their consent to participate. Patients admitted for epilepsy surgery evaluation, those not fluent in English, and those with learning disabilities were not approached. Participants' gender (male/female), age (years), the length of time they had experienced seizures (years), the frequency of their seizures (number per month), the number of times they had been admitted to hospital in an emergency with seizures (emergency admissions), and their current AED use were recorded. All participants completed the Hospital Anxiety and Depression Scale (HADS) (Zigmond and Snaith, 1983) and the Trauma History Questionnaire (THQ) (Green, 1996). The Graded Naming Test (McKenna and Warrington, 1983) and the Test for Reception of Grammar (Bishop, 2003) were carried out by the recruiting neurologist used to assess linguistic competence.

The 20 patients described in this study all received a clear diagnosis of epilepsy or PNES after their period of admission at the Royal Hallamshire Hospital. Diagnoses were confirmed by assessment of clinical history, video-EEG recording of a typical seizure involving impairment of consciousness, confirmation of the recorded seizure as typical by patients and witnesses, and scrutiny of ictal electro-clinical appearances by fully trained neurophysiologists. The neurophysiologists did not consider any of the 20 patients described in this study to have a dual diagnosis of epilepsy and PNES.

2.2 Interview method

Participants were interviewed in a video-EEG suite when they attended the unit as inpatients for video-EEG observation. Participants were interviewed by a Consultant Neurologist (MR) who was unaware of the findings of the video-EEG recording at the time of the interview and who had not met them previously. The interactions were video-recorded using the pre-installed video equipment in the video-EEG room at the Royal Hallamshire Hospital in Sheffield. A third party (not the author) transcribed the interactions.

As described in chapter two, interviews were conducted following guidelines initially developed by the 'EpiLing' project in Bielefeld, Germany (Gulich and Schoendienst, 1999; Schoendienst, 2001; Furchner, 2001; Surmann, 2005, cited in Schwabe et al, 2008). A pilot study in the UK had demonstrated that the semi-standardized interview procedure could be replicated in English with similar sociolinguistic findings (Schwabe, Howell and Reuber, 2007). Further details of the ('EpiLing') interview method can be found in chapter two. The approximate duration of specified enquiry phases of the ('EpiLing') interview method used in the encounters is detailed in figure 1 below.

Figure 1: 'EpiLing' interview structure (adapted from Plug, Sharrack and Reuber, 2009c).

Interview phase	Inquiries	Approximate duration
"Open" beginning	"What were your expectations when you came to hospital?" or "How can I help you today?" (Avoid reference to seizures)	10 minutes
Elicited accounts of individual seizure episodes	"Can you tell me about the first seizure you can remember?" "Can you tell me about the last seizure you can remember?" "Can you tell me about the worst seizure you can remember?"	10 minutes
"Challenge"	Inquiries or inquiry challenging the patients' description Direct questions about items not covered in the previous phases of the interview (e.g., about past medical history, medication, employment, driving) may be covered here.	5 minutes
Topic shift	The seizures are obviously quite distressing for you, but can you tell me about things which you enjoy doing?	5 minutes

2.3 Analytical approach

Verbatim transcripts were coded and analysed using content analysis methods. Content analysis is a procedure for making inferences by methodologically and objectively identifying the characteristics of messages (Holistic, 1969). Most commonly used in the social sciences, content analysis involves the rigorous analysis of words or themes to assess the presence, meaning and relationships between concepts in order to extract quantifiable measurements (Krippendorff, 1980). A qualitative approach to content analysis was taken in this study. Weber (1990) has defined such an approach as going beyond simply counting words to examining, grouping and analysing themes and categories in data.

Heish and Shannon (2005) have described three approaches to qualitative content analysis, conventional, directed and summative. In conventional content analysis, no prior assumptions or hypotheses are made and coding categories are generated directly from the data. If code development is initially guided by a theory or previous research findings then a directed (or deductive) approach is taken. A summative approach involves counting or comparing keywords or content, followed by an analysis of the underlying context of the data examined (Heish and Shannon, 2005).

The development of codes in this analysis was an iterative process that began with some assumptions based on previous work. As described by Joffe and Yardley (2004), code development was initially governed by ideas the author brought to the data. That is, findings from existing research (as described in chapter two) helped to guide the research questions addressed in the analysis. Consequently, a directed (or deductive) approach to content analysis was taken in this analysis.

For example, the primary objects of study in the analysis were references made by patients to others not present in the encounters (third parties). In chapter two, it was considered that the analysis of third party references should not be confined to patient descriptions of reduced consciousness. It was also argued that third party reference use should be examined both when patients described what had happened during attacks and when they discussed their seizure condition more generally (for example, when they reported how they coped with

the condition). Similarly, a hypothesis developed to suggest that patients with PNES might reference third parties in more 'negative' contexts than people with epilepsy, who may reference third parties in more 'positive' contexts (these concepts are described later in the chapter, see 'Coding frame development').

This is not to say that the codes used in this analysis were predetermined and applied with immediate effect. However, that codes were developed from predetermined points of interest derived from the study design and findings from the literature review (presented in chapter two), and subsequently shaped by what was found in the data.

The final and complete set of codes used in a content analysis is referred to as a coding frame. As is common in most content analyses, during the development of the coding frame used in this study categories were split, merged, linked, spliced and refined (Joffe and Yardley, 2004).

The approach taken to coding frame development, the development of codes and how these came to be defined and operationalized in the final coding frame is presented below.

2.4 Coding frame development

Given that a third party transcribed the video-recordings, transcripts were analysed alongside video-recordings to help ensure that the transcription was correct and for clarification. During the development of the coding frame, coding categories (and how these were defined and operationalized) were regularly discussed with thesis supervisors (PD, MR and TW). The author remained blinded to patients' diagnoses during the development and application of the coding frame.

A flow chart presented in the Appendix outlines the process of code development followed in this analysis (see Appendix, Figure 2).

2.4.1 Third party references

The process of coding frame development began by identifying all instances in the data where patients referenced others not present (third parties). Third party references were initially defined as references to someone (for example, 'my husband') or persons (for example, 'my family') not present during the patient's conversation with the doctor.

It was initially conceived that a third party reference would be identified each time the patient referenced someone not present in their conversation with the doctor. However, during the development of the coding frame it was observed that patients often referenced the same third party a number of times in the course of discussing the same topic (in the same topical segment of the conversation).

In most cases, third parties were named and/or their relationship to the patient described, or another identifying characteristic attached to the third party when introduced (or later re-introduced) by patients into the conversation; for example, '*Malcom, my husband*', '*the nurse on the ward*', '*Doctor Green, at Guys*'. Where the third party was referenced again in the course of the same topical discussion, patients were typically observed to use pronouns to describe the third party; for example, '*he*' or '*she*'. This pattern of communication has been observed in conversations in other settings (Gundel, Hedberg and Zacharski, 1993).

On the basis of these considerations, it was concluded that if third party references were counted individually (at each point a reference was made) the number of third party references in the data may be over-represented. This could have skewed later analyses examining the frequency and use of third party references by people with epilepsy and PNES. Therefore, it was deemed necessary to identify, group and code references to the same individual (third party) within the parameters of conversational topical boundaries.

Krippendorff (1980) observed that a topical segment is content that shares a commonality. When identifying topical segments in the data, commonality was examined in the context of manifest content. As described by Graneheim and Lundman (2004), 'manifest' refers to the descriptive level of content present and

visible in the data. In this sense, the latent content - the underlying (often multiple) meanings of the text (Graneheim and Lundman, 2004) were not taken into account when identifying the topical content parameters of third party references at this stage of the analysis.

The linguistic and conversational methods used by participants to achieve topic change were also considered. Doctors' questions are recognised to set agendas and signal topic changes in doctor-patient interactions (Boyd and Heritage, 2006). Similarly, in the interactions examined here, the doctor's questions often signalled a change in the topic of the conversation; these questions occurred more frequently towards the end of consultations. Prefatory disjunctives were sometimes used by the doctor (and, to a lesser extent, patients) to signal a change in conversational topic was to follow (as described by Drew and Holt (1998), these are similar to 'cue phrases' and include markers such as, *'well'*, *'anyway'* and *'alright'*).

Topic changes in patients' narratives were often signalled by the use of declarative clauses (information-giving statements), in which new content was introduced. Geluykens (1993) has observed that declarative clauses are the least obtrusive way of introducing a change of topic. In the data, patients rarely used explicit expressions to mark the beginning of a change in topic (as described by Geluykens (1993), these include expressions such as, *'I'll tell you something else'* and *'on another topic'*). As previously observed by Howe (1991), patients sometimes used formulaic expressions (such as, *'that reminds me'* and *'speaking of that'*) to signal the introduction of new information and a change in topical content. Finally, as observed by Drew and Holt (1998), participants sometimes 'closed down' the topic under discussion by concluding their descriptions with 'summary assessments' or, less frequently, 'figurative expressions' (for example, *'in the nick of time'* and *'at the end of the day'*).

However, the procedures that conversationalists utilise to achieve topic change (Maynard, 1980) were only considered pointers for potential transitions in topic change. Topical changes in the conversation were primarily considered in relation to changes in the manifest content of patient talk.

Following the work of Rohde and Frank (2011), the boundaries of topical content in this analysis were ultimately defined as discourse consisting of an

utterance or series of utterances centered on a shared topic. Topical discourse areas could consist of an utterance or sequences of utterances that transparently referred to the same object or topic. Or in less explicit cases, a sequence of utterances spanning a set of observations exchanged on the same topic.

For example, in extract 3a below, the doctor questioned how the patient (Patsy, a patient with PNES) knew she didn't lose consciousness during an attack, "So what, how do you know you didn't lose consciousness, how do you know that?" (lines 314 to 315). In response, Patsy spontaneously referenced a colleague at work, "the other (aid at the time)" (line 316). Patsy referenced the same colleague again at lines 318 ("she came straight away") and again at line 319 (when she paraphrased what the "aid" had told her, "she said that"). Following a pause, Patsy concluded her response with a summary assessment, "I didn't lose consciousness" (lines 320 to 322). The doctor's next question signalled a (potential) change in topic, the doctor asked Patsy if she could remember falling during the attack, "Could you remember falling?" (line 324). In the response that followed (not shown here), Patsy made no mention of a third party.

The additional references to the third party shown in the extract below (at lines 318 and 319) were within the bounds of the same topical conversation, how Patsy knew she did not lose consciousness during the attack. In the extract, only one third party reference to the "aid" (line 316) was identified and coded for in the final analysis.

Extract 3a

314. D: So what, how do you know you didn't
315. lose consciousness, how do you know that?
316. P: Because the, the other (aid at the time)
317. I was working with witnessed (it)
318. (and) she came straight away, to, to pick me up
319. off the floor, and she said that,
320. all I was, I did know where I was and
321. (who) I was, you know, (like that) ((1 second))
322. I didn't lose consciousness.
323. D: Could you remember falling?
324. Or is it too long ago now?

In the final coding frame, patients were identified as referencing a third party when they mentioned a family member, partner, friend, colleague, medic, passers-by, persons, or anyone – named or otherwise during their conversation with the doctor. However, after a third party had been named or identified by the patient, subsequent pronouns (or other identifiers) used to reference the same third party were not counted if made in the bounds of the same topical segment of the discussion. These third party references were labelled as '(seizure and non-seizure-related) third party references'.

2.4.2 Seizure-related third party references

Following the development of the '(seizure and non-seizure-related) third party references' code, it was evident that some of the third party references identified in the data did not appear at all connected with patient's seizure experiences. It was therefore necessary to refine what constituted a third party reference for the purpose of the analysis.

As described in chapter two, authors have observed that people with seizures often reference third parties when they describe what has happened during attacks. For example, patients have been shown to reference third parties when contoured 'gaps' in consciousness, when adding to their own (subjective) recollections of events, when describing the situations in which seizures have taken place, and when discussing the immediate aftermath of seizures (for example, physical injuries) (Gulich and Schoendienst, 1999; Schoendienst, 2001; Furchner, 2002 and Surmann, 2005, cited in Schwabe et al, 2008; Schwabe, Howell and Reuber, 2007 and Plug, Sharrack and Reuber, 2009a).

However, people with seizures have also been observed to reference third parties when they describe their seizure condition more generally. For example, when they describe how they cope with the condition (Reuber and Monzoni, 2009), their dependency on others (Reuber, 2008), their experiences of social isolation (Thompson et al, 2009), and in the context of previous medical treatment (Thompson et al, 2009 and Plug, Sharrack and Reuber, 2009c).

Given these findings, it was previously suggested (in chapter two) that exploration of third party references should not be confined to descriptions of

periods of reduced self-control, or restricted to discussions of what patients describe as having happened during attacks.

During coding frame development, the topical content of '(seizure and non-seizure-related) third party references' was examined to determine whether the third party references made by patients concerned their seizure experiences and/or their seizure condition.

'Seizure-related third party references' were made when patients referenced third parties that had witnessed attacks, those who may have witnessed the patient's state, or those to whom the patient spoke in the aftermath of attacks. Third parties referenced when patients described how they managed their seizures, how they coped with the condition, the impact of having seizures on their day-to-day lives, and how they felt others perceived their condition were also labelled 'seizure-related third party references'.

For example, in extract 3a above, Patsy described that she knew she didn't lose consciousness during an attack as a third party had "witnessed (it)" (line 317). Patsy described the third party coming to her aid, "she came straight away, to, to pick me up" (line 318). Patsy also paraphrased what the third party had noticed ("she said that", line 319) about her level of consciousness (her level of responsiveness), "I did know where I was and (who) I was, you know, (like that)" (lines 320 to 321). Patsy referenced the third party during a discussion in which she described what had happened during a seizure episode.

Whereas in extract 3f, Betty discussed a third party ("ask people", line 168) in relation to her seizure symptoms, "can't remember" (line 169) and "forgetting" (line 174). However, when Betty referenced the third party, the context of her description was not limited to a period of reduced self-control or restricted to what had happened during an attack. Betty described the potential impact of her seizure symptoms (keeping her job), "I'm worried about keeping me job if this carries on" (lines 173 to 174).

In the final coding frame 'seizure-related third party references' were identified as occurring when patients referred to third parties not present during their conversation with the doctor when, in describing their seizure experiences

and/or their seizure condition, they mentioned a family member, partner, friend, colleague, medic, passerby, persons, or anyone – named or otherwise.

Following the caveat described previously, after a third party had been named or identified by the patient, subsequent pronouns (or other identifiers) used to reference the same third party were not counted if made in the bounds of the same topical segment of the discussion.

Third party references unconnected with any seizure experience or discussion of the patient’s seizure condition were labelled ‘non-seizure third party references’. An example of a ‘non-seizure third party reference’ is presented below. The extract was taken from Kelsey’s consultation, a patient with PNES.

Extract 3b

176 P: Yeah he was, (son’s name), was born completely normal
177 he started (0.9) (self) and a lot of other
178 doctors (0.3) have agreed the MMR jab did it.
179 D: Mm
180 (0.2)
181 P: But (0.4) That’s () they won’t let me say it
184 ()
185 D: Mm
186 P: In my, my er personal opinion that’s what
187 caused him to be autistic. The MMR jab.

As can be seen above in extract 3b, Kelsey referenced her son (“he” and (son’s name), line 176, “he” (line 177) and “him” (line 187)) during a conversation in which she discussed the (possible) cause of her his autism. During this discussion, Kelsey also referenced the opinions of medical professionals, “a lot of other doctors (0.3) have agreed the MMR jab did it” (lines 177 to 178) and “they won’t let me say it” (line 181). However, as can be seen, Kelsey did not reference these third parties in relation to her seizures experiences or her seizure condition.

2.4.3 Spontaneous and prompted third party references

During code development it was recognised that some of the ‘seizure-related third party references’ identified in the data were spontaneously made by patients, whereas others resulted from prompting by the interviewer (doctor).

As detailed below, three categories of ‘seizure-related third party references’ were identified in this respect.

- 1) ‘All seizure-related third party references’ (the total sum of ‘seizure-related third party references’ regardless of whether these were made spontaneously by patients, or prompted by the interviewer.)
- 2) ‘Spontaneous seizure-related third party references’ (the patient spontaneously referenced a third party without being asked or prompted to do so).
- 3) ‘Prompted seizure-related third party references’ (the patient was prompted to discuss a third party, the interviewer specifically asked the patient to discuss/explore a third party reference).

If patients were prompted to discuss a third party they had previously (spontaneously) referenced, the former was classified as a ‘spontaneous seizure-related third party reference’ and the latter was classified as a ‘prompted seizure-related third party reference’.

During coding frame development it was observed that the doctor typically named third parties or discussed third parties in terms of identifying characteristics when he prompted patients to discuss them (for example, ‘*what did the nurse say about that?*’, ‘*did your husband see that happen?*’) Consequently, patients often referred to third parties using pronouns (for example, ‘*he*’, ‘*she*’, ‘*they*’) after they had been prompted to discuss these.

Therefore, in the final coding frame, if the patient referenced a third party after they had been prompted by the interviewer to do so and used (for example) a pronoun to do this, it was considered a ‘prompted seizure-related third party reference’ and coded as such. If the patient used subsequent pronouns (or other identifiers) to reference the same third party in the bounds of the same topical segment of the discussion the additional references were discounted.

An example of a patient with epilepsy (Jack) that spontaneously referenced his partner (“wife” at line 203) is presented below in extract 3c.

Prior to the patient making the third party reference (“wife” at line 203), the doctor (interviewer) questioned whether the two seizures Jack had discussed (“two of the seizures”, line 194) were the only seizures that Jack had experienced (“two in your life?”, line 196). After Jack had clarified that the two seizures to which he referred were experienced in hospital (“No no no, two, two here”, line 197), the doctor asks Jack whether the two seizures were typical of the other seizures he had experienced (“these were the only ones like that ever, or?”, lines 198 to 199). In this exchange, the doctor did not prompt Jack to discuss a third party.

Jack confirmed that the seizures, to the best of his knowledge, were typical of others experienced (“As far as I can remember, yes, as far as I can remember”, lines 200 to 201). Expanding on this initial account, Jack spontaneously referenced his “wife” (at line 203) and explained, “Most of the time I have to ask my wife what’s happened, because I don’t know (1.5)” (lines 203 to 204).

Extract 3c

191 P: Had a seizure and I didn’t know I was having one
192 until I saw it written down on the (1.5)
193 and I was sitting (six o clock) (-) I’m (standing
194 up) too so two of the seizures were (in fact that)
195 (1.5)
196 D: Two in your life?
197 P: No no no, two, two here
198 D: Sure, these, we, these were the only ones like
199 that ever, or?
200 P: As far as I can remember, yes, as far as I can
201 remember.
202 (0.8)
203 P: Most of the time I have to ask my wife what’s
204 happened, because I don’t know (1.5) I usually
205 wake up and find that I’ve bitten my tongue,
206 and cheek and all that (you know intern), (inside)
207 (0.9) (but I) (1.2) I (1.3) I think these last ones,
208 I had to have (on) (dentures)(because)
209 I (and) the tablets that I took
210 did damage to my gums, (1.2) and I had to have
211 (dentures put in).
212 (1.2)

An example of a patient (Ken, a male patient with epilepsy) that was prompted by the doctor to discuss a third party is presented below in extract 3d.

In what appeared to be an attempt to frame the time in which he regained consciousness during an attack, Ken mentioned the arrival of an ambulance, “By the time I’d come round, the ambulance had actually, just about arrived” (lines 350 to 352). Following this, Jack discussed a period of time in which he could not remember what had happened (lines 356 to 367). Later in the encounter, the doctor asked Jack, “But you can remember the ambulance men coming or, er were they already there?” (lines 368 to 369). Prompted by the doctor, Jack responded, “they were already there I think” (line 373). Here “they” (line 373) referred to the “ambulance men” (line 368), and the reference was labelled a ‘prompted seizure-related third party reference’.

Extract 3d

350 P: By the time I’d come
351 round, the ambulance had
352 actually, just about arrived.
353 (0.5)
354 D: Mhmh
355 (0.7)
356 P: So, and I couldn’t remember anything
357 for about half an hour either, (1.3) that was
358 the scary bit.
359 (0.3)
360 D: Which half hour could you not remember?
361 (0.5)
362 P: Erm (1.0) I couldn’t remember for the half
363 an hour afterwards,
364 D: Mh.
365 P: Couldn’t remember anything, (1.4) where i was,
366 (.) who I was, or (.) anything really.
367 (1.3)
368 D: But you can remember the ambulance men coming
369 or, er were they already there?
370 P: ()
371 D: When you came round?
372 (0.4)
373 P: They were already there I think
374 D: Mh mh.
375 (1.2)
376 P: I mean I remember it all now, but it is,
377 at the time when you actually there, you
378 don’t remember, it’s like, what’s going on?
379 You know.

2.4.4 Patient's relationship to the third party referenced

In addition to identifying the number and type (all, spontaneous and prompted) of 'seizure-related third party references' in the data, it was possible to establish the patient's relationship to the third party referenced. Following a thematic analysis of the 'seizure-related third party references' identified, eight mutually exclusive patient-third party reference relationship categories emerged from the data: partner, family member, friends and acquaintances, medical, employment, other institutional, unknown others and unknown. In addition, it was considered that partner, family member, and friends and acquaintances references could be combined to form the category 'socially intimate references'. The patient-third party reference relationship categories identified in the data are described in more detail in figure 2, below.

Figure 2: patient-third party reference relationship categories.

Relationship	Description
Partner	The patient's partner (for example, spouse, girlfriend, boyfriend; past or present).
Family member	A member of the patient's family, excluding that of partner, (for example, son, daughter, mother, father, brother, sister, niece, nephew, cousin).
Friends and acquaintances	Someone the patient knows socially (for example, a friend or neighbour).
'Socially intimate' references	The sum total of partner, family member, friends and acquaintances references.
Unknown others	Someone unknown to the patient (for example, 'someone helped me', 'a man approached me', 'I came round and a woman was standing over me').
Medical	A member of the medical profession (for example, doctor, nurse, psychiatrist, paramedic).
Employment	A work colleague, employer or customer in a place of work (for example, boss, colleague, assistant).
Other institutional	A member of another institution, excluding 'medical' and 'employment' institutions, (for example, police men, firemen, dentists, teachers).
Unknown	The third party reference could not be identified, or fell outside of other categories (for example, reference to a pet).

An example of a patient with PNES (Vera) that referenced an 'unknown other' 'seizure-related third party' is presented below in extract 3e. At line 311, Vera referred to a "man" that was present after she had come to following a seizure. Vera described that she did not know the "man", "I don't know who, it, he (line 312), and that she thought he had come from the petrol station (lines 312 to 315).

Extract 3e

304 P: I was going to the bus stop,
305 to catch the bus, and next minute,
306 er, I was just coming round,
307 em, (0.9) er, I was, I must have been
308 laid a, er, I must have been laid
309 on the pavement, or something (1.1),
310 and, er, when it comes to,
311 there was a man at side of me,
312 I don't know who it, he, I think he'd come,
313 I know there was a,
314 a, (0.6) where
315 you go and get your (.) petrol from

An example of a patient with PNES (Betty) that referenced an 'employment' 'seizure-related third party' is presented below in extract 3f. The context of 'employment' is evident at lines 167 and 175 ("work") and at line 173 ("job"). At line 168, Betty referenced a third party, "ask people, what I've done".

Extract 3f

167 P: If it happens at work I have to
168 ask people, what I've done; because I
169 can't remember,
170 (0.6)
171 D: hm
172 (1.2)
173 P: (this is why) I'm worried about keeping me job,
174 if this carries on, because I'm forgetting what
175 I've done, it's work the end of the day, in it?

Other examples illustrating the different types of 'seizure-related third party references' in terms of their relationship to the patient can be found at:

'Partner': In extract 3c, Jack referenced his "wife", "Most of the time I have to ask my wife what's happened" (lines 203 to 204).

'Family': In extract 3h, Sandra referenced her "kids" (line 97), and later referred to them as her "two boys" (line 98) and "they" (lines 99 and 104).

'Other institutional': In the Appendix, extract 2, Barbara referenced an 'other institutional' third party, "police" (line 100), also referred to as "they" (line 97).

'Friends and acquaintances': In extract 3g, Henry referenced his "friends", "me friends are well aware of it" (lines 182 to 183), and described, "we all live together in a group" (lines 183 to 184).

'Medical': In the Appendix, extract 3, Carl described his experience of a hospital visit ("which have resulted in me going to the hospital", lines 1038 to 1089), and referenced medical professionals, "they're dealing with an area", (lines 1043 to 1044).

'Unknown': In the Appendix, extract 1, Laura referenced an 'unknown' third party, "dogs" (lines 202 and 203).

2.4.5 'Seizure-related third party references' used in 'catastrophising' and 'normalising' accounts

In the final stage of coding frame development a different approach was taken to the development of codes. Whereas the manifest content of the data was analysed in the development of the codes described above, in the next stage of code development the latent content of the data was examined. As described by Graneheim and Lundman (2004), this necessitated moving beyond examining what was present and explicit (manifest) in the data and interpreting the underlying meaning or inferred meaning of the text.

As described in chapter two, authors have observed that people with epilepsy may use third party references to bolster subjective seizure accounts, and add third party accounts to their own recollections of events to describe periods of reduced consciousness (Schwabe et al, 2008; Schwabe, Howell and Reuber, 2007 and Plug, Sharrack and Reuber, 2009a). People with epilepsy have also been shown to use third party references to bolster accounts of positive coping styles (Reuber and Monzoni, 2009).

In contrast, people with PNES have been observed to use third party references to orientate the discussion around the (dramatic) circumstances or consequences of seizures (Schwabe, Howell and Reuber, 2007 and Plug, Sharrack and Reuber, 2009a). People with PNES have also been shown to use third party references to express doubt about others, perceived doubt about themselves by others (including by medical staff) (Thompson et al, 2009) and

dissatisfaction with previous medical treatment (Plug, Sharrack and Reuber, 2009c). In addition, authors have observed that people with PNES report feeling isolated (Thompson et al, 2009).

Considering these findings, it was previously suggested (in chapter two) that people with PNES might reference third parties in more 'negative' contexts than people with epilepsy, who might use third party references to contribute to or support more 'positive' accounts of their seizure experiences and how they cope with the condition.

During the development of the coding frame, 'seizure-related third party references' identified in the data were analysed to see if these could be delineated as used in 'positively' or 'negative' orientated, or 'neither positively or negatively' orientated, accounts.

'Positively' orientated accounts were initially conceptualised as including instances where patients referenced 'seizure-related third party references' and they described: capably reacting to seizures, confidence in managing the condition, mitigating seizure-related risks to engage in activities, demonstration of (other) effective coping strategies, an optimistic outlook/attitude towards seizures and/or seizure prognosis, or downplaying the potentially dangerous situations in which seizures had taken place and/or the consequences of seizures.

'Negatively' orientated accounts were initially conceptualised as including instances where patients referenced 'seizure-related third party references' and they described: the dramatic situations and circumstances in which seizures had taken place, encountered seizure dangers (including injuries), avoiding activities because of seizure-related risks, a pessimistic outlook/attitude towards seizures and/or seizure prognosis, the possible negative consequences of seizures, a lack of confidence in managing the condition, and poor coping strategies.

It was found that over one half of the 'seizure-related third party references' identified in the data during the development of the coding frame could broadly conceptualized as taking place in the context of 'positively' or 'negatively' orientated accounts.

'Seizure-related third party references' identified in the data that appeared to be used in 'positively' or 'negatively' orientated patient accounts were analysed in more depth to see whether tangible definitions of these (and possible sub-categories) could be developed for use in the final coding frame.

Thematically, it was observed that the 'positively' or 'negatively' orientated 'seizure-related third party references' identified in the data could be grouped into accounts that related to patients seizure experiences and the circumstances and consequences of seizures, the strategies used to cope with seizures, and the impact of seizures on social relationships. As presented below, in figure 3, further sub-categories derived from these themes were developed.

Figure 3: Thematic analysis of 'positive' and 'negative' contexts

Thematic analysis of 'positive' and 'negative' contexts	The third party reference was used in a 'positive' or 'negative' context to describe:	
Seizure experiences, circumstances and consequences	Seizure experiences	How they felt or what they thought about a seizure episode (or a typical seizure episode)
	Seizure circumstances	The situations or circumstances in which seizures had taken place
	Reactions of seizure witnesses	How others had reacted to witnessing a seizure
	Seizure injuries	The injuries they have sustained as a result of seizures
	Medical treatment	Medical investigations of their seizure condition and medical treatment they had received because of seizures
Coping strategies	Seizure experience	How they cope with experiencing seizures, including strategies to interrupt seizures
	Seizure (condition) management	Strategies used to manage and cope with the condition and to minimise seizure-related risks
Social relationships	Social support/dependency	Social support networks, how these were utilised, and if they felt dependant on others
	Social inclusion/isolation	The extent that they felt socially included or excluded (isolated) because of their seizure condition

However, during the analysis it was realised that the 'seizure-related third party references' used in 'positively' or 'negatively' orientated accounts, the categories that emerged from these (seizure experiences, circumstances and consequences, coping strategies, and social relationships) and the subsequent sub-categories developed from these themes (as presented in figure 3) could not be defined and conceptualized concretely enough to make them mutually exclusive. Mutual exclusivity means that no data should fall between categories (or codes) or fit into more than one category (or code) (Krippendorff, 1980).

Overlap between 'positive' and 'negative' contexts was sometimes observed. Similarly, there were numerous instances in the data where a 'seizure-related third party reference' was used in the context of describing one or more of the ('positive' or 'negative') sub categories conceptualized during code development (that is, across seizure experiences, circumstances and consequences, coping strategies, and/or social relationships sub-categories). Moreover, considerable intersection of the sub-categories derived from these three themes (presented in figure 3) was observed the deeper the data was abstracted.

This is not an uncommon occurrence in data of this nature. As Graneheim and Lundman (2004) have observed, "*owing to the intertwined nature of human experiences, it is not always possible to create mutually exclusive categories when a text deals with experiences*" (p107).

It was therefore decided that the development of sub-categories derived from 'seizure-related third party references' used in 'positively' or 'negatively' orientated patient accounts should be abandoned. Instead it was decided to re-examine 'seizure-related third party references' used in 'positively' or 'negatively' orientated accounts in an attempt to identify tangible concepts with narrower definitions; in the hope that these could be more concretely applied to the data and coded for in the final analysis.

A review of the 'seizure-related third party references' used in 'positive' or 'negative' contexts identified during coding frame development revealed that many of these references seemed to serve the purpose of 'normalising' or 'catastrophising' the patient's experience.

In the final coding frame, 'normalising' displays were coded when, in describing their seizure experiences or their seizure condition, participants referenced a third party and expressed 'troubles resistance', 'downplayed' or seemed not to treat the problem (for example, seizure occurrence) as serious, and minimised the perceived or encountered 'dangers' (consequences) of seizures or the emotional or social impact of having seizures in their account. These were labelled 'normalising - seizure-related third party references'.

'Troubles resistance' has been well defined and documented in the literature about communication both in ordinary social interactions between family and friends (Jefferson 1984) and in medical care; it involves patients describing problems and then demonstrating how they overcame them (Heritage and Robinson, 2006). 'Normalising' activities have also previously been described in a study exploring interactional and linguistic displays of coping with epilepsy (Reuber and Monzoni, 2009).

Castrophisation has been well documented in the medical (especially the pain) literature (Sullivan et al, 2001; Smeets et al, 2006; Bartley and Rhudy, 2008 and Fabian et al, 2011). Following an established definition (Sullivan et al, 2001), in the final coding frame, 'catastrophisation' was coded as a distinct construct comprising three correlating dimensions of 'magnification, rumination and helplessness' resulting in an 'exaggerated negative mental set'. These were labelled 'catastrophising - seizure-related third party references'.

'Magnification' means to amplify the significance of something (for example, the symptoms of distress), to place a great deal of emphasis on something and/or to make something seem greater or more important than it is. 'Rumination' means to repeatedly think deeply and carefully about something, this may involve in-depth reflection, deliberation and contemplation. 'Helplessness' relates to an inability to do something to make a situation (or something) easier or better, the situation may be described as beyond control; 'helpless' individuals may describe themselves as somehow defenceless, vulnerable or as feeling overwhelmed.

In the context of pain research, Sullivan et al (2001) conceptualised catastrophisation as "*an exaggerated negative 'mental set' brought to bear during actual or anticipated [pain] experience*" (p53). In this sense, Sullivan and

colleagues do not (technically) require that catastrophisation necessitates (for example) anticipation of negative events, pessimistic predictions or thoughts about 'bad possibilities'. However, in the analysis presented here (as in the work of other theorists, for example Keefe et al, 1999), 'catastrophisation' was defined as including the anticipation of (negative) experiences.

During coding frame development, it was observed that more than one 'seizure-related third party reference' was sometimes used in accounts that 'normalised' or 'catastrophised' the patient's experience. In order that 'catastrophising - seizure-related third party references' and 'normalising - seizure-related third party references' were not over represented in the final analysis, it was necessary to stipulate that at least one 'seizure-related third party reference' was used in accounts that 'catastrophised' or 'normalised' the patient's experience. This meant that if two or more 'seizure-related third party references' were used in the same 'catastrophising' or 'normalising' account that these were counted as a single 'catastrophising - seizure-related third party reference' or a 'normalising - seizure-related third party reference'.

Following this, if the doctor did not prompt the patient to discuss a third party, and the patient spontaneously referenced a 'seizure-related third party' in the course of a 'catastrophising' or 'normalising' account, then this was regarded as a single 'normalising - spontaneous - seizure-related third party reference' or a 'catastrophising - spontaneous - seizure-related third party reference', regardless of the number of third parties referenced by the patient in the account in which they 'catastrophised' or 'normalised' their experience.

If the doctor was observed to prompt the patient to discuss a third party, and in responding to the request the patient used a 'seizure-related third party reference' to 'catastrophise' or 'normalise' their experience, then this was regarded as a single 'normalising - prompted - seizure-related third party reference' or a 'catastrophising - prompted - seizure-related third party reference'. Regardless of the number of third parties referenced by the patient in the account in which they 'catastrophised' or 'normalised' their experience.

An example of a 'prompted - seizure-related third party reference' in which 'normalisation' was demonstrated is presented below in extract 3g. Taken from an interview with Henry, the doctor explicitly prompted talk about a 'third party',

“What do your friends tell you about the seizures?” (line 174). In response, the patient attributed a ‘normalising’ account to them.

In this account, Henry ‘downplayed’ the seriousness of seizure occurrence. Following the doctor’s question, Henry began his response with, “Well nowt really” (line 175). In doing so, Henry minimised what his friends had noticed about his seizures, and framed the occurrence of his seizures as apparently ‘overlooked’ by his friends. This is despite the fact that Henry reported, his “friends are well aware of it and that like so” (lines 182 to 183). Thus, despite Henry’s friends being “well aware” of his seizures/his condition, Henry framed them as not treating the occurrence of seizures as serious.

In his account, Henry attributed the report, “just had another seizure” (line 176) to his friends and went on to describe that his friends sometimes called his seizures “funny turns” (line 179). In addition, Henry’s use of language during his account (for example, “just’, line 175 and 176) appeared to minimise the seriousness of his seizures.

Moreover, the social impact of Henry’s seizures was minimised in his account. Henry described that, his “friends are well aware of it” (lines 182 to 183) and that they “all live together in a group so” (lines 183 to 184). In the account, Henry also downplayed the emotional impact of his seizures, he explicitly stated that he was “alright, there’s no problems” (lines 181 to 182).

Extract 3g

174 D: What do your friends tell you about the seizures.
175 P: Well nowt really. They just (0.3) they
176 just tell me I’ve just had another seizure (1.5)
177 Or I’ve had one of my funny turns like as
178 they sometimes call it.
179 D: Mm
180 (0.7)
181 P: Er (0.7) other than that I’m alright, there’s
182 no problems (2.5) me me me friends are well
183 aware of it and that like so (0.3) We all live
184 together in a group so (1.1) ((coughs))

An example of a ‘spontaneous - seizure-related third party reference’ demonstrating ‘normalisation’ is presented below in extract 3h. The excerpt is taken from an interview with Sandra who has epilepsy.

At lines 86 to 88, the doctor probed a previous account Sandra had given earlier in the interview, in which she briefly discussed symptoms of anxiety as a potential trigger for her seizures. However, as is evident in the extract, the doctor's question did not contain any mention of third parties, "(You say) it's more when, you, when you get more anxious. More anxious about anything in particular about the seizures, or?" (lines 86 to 88).

In her response, Sandra minimised the emotional impact of having seizures, she described that she was 'not worried' and was "used to" having seizures, "I don't worry about, don't really worry about that" (lines 89 to 90), "I'm sort of used to them" (lines 90 to 91), "You get used to em being there" (line 92).

In what appears to be an attempt to legitimise and bolster this account, Sandra reported how her "husband" (line 94) typically reacted to her having a seizure. In her account, Sandra framed her husband as not seeming to treat the problem (seizure occurrence) as serious. Sandra described that her husband, "just takes no notice anymore", and reported his speech, "just uh, "you alright?"" Expanding on this account, Sandra further downplayed her husband's reaction to her seizures when she stated, "well in fact he don't even say alright anymore" (lines 96 to 97).

Sandra then referenced her "kids" (line 97), "two boys" (line 98), and described their reactions as similar (almost identical) to that of her husband's. Sandra described her "kids" reactions as minimal, "it's like it's not happening you know" (lines 99 to 100). Sandra further downplayed her "boys" reaction when she reported that, they "don't even say "you alright?" anymore" (lines 100 to 101).

Finally, Sandra reported that both she and her family were so used to the seizures occurring (and the impact was so minimal) that she and her family no longer took any notice, "they're that used to me fitting that I don't, an they don't, take any notice because I do it every day" (lines 101 to 104).

For reasons previously described, despite the presence of two third party references in the extract presented below (one relating to Sandra's spouse or partner ("husband"), and the other relating to Sandra's family ("boys", "kids")),

the extract was labelled as a (one) display of 'normalisation' (a 'normalising - spontaneous - seizure-related third party reference') in the final analysis.

Extract 3h

84. D: Hmm
85. (2.5)
86. (You say) it's more when, you, when you get
87. more anxious. More anxious about
88. anything in particular about the seizures, or?
89. P: Oh no, I don't worry about, don't really
90. worry about that because uh, I'm
91. sort of used to em after so many years
92. Just, (1.3) you get used to em being there.
93. D: Hmhm.
94. P: Uh, me husband just takes no notice anymore. He
95. just uh, "you alright?"
96. it, it, well in fact he don't even say alright
97. anymore, he just, hh, I mean even kids, I've got
98. two boys, sixteen and eighteen an' (1.3) it's
99. like it's not happening you know, they jus', (2.0)
100. you know, don't even say 'you alright?'
101. anymore, it's jus', hh (1.1), they're that used to me
102. fitting that
103. D: Hm hm
104. P: I don't, an they don't, take any notice because
105. I do it every day.

An additional example of a 'spontaneous seizure-related third party reference' used to 'normalise' the patient's experience is presented in the Appendix (see Appendix, extract 3). The excerpt was taken from an interview with Carl, who has epilepsy.

Extract 3i below details a 'spontaneous seizure-related third party reference' used to 'catastrophise' the patient's experience. The excerpt was taken from an interview with Sue, a patient with PNES.

Sue spontaneously volunteered mention of a third party, "me husband" (at line 251). Prior to this reference, Sue discussed attending an educational establishment (not shown in the extract). During this narrative, the doctor did not ask Sue to discuss any third parties.

In the extract below, Sue 'catastrophised' her experiences. In her account, Sue's negative mental set was evident; she used the terms, "afraid" (line 254),

“frightened” (line 256), “endanger” (line 276), “worry” (line 284), “worrying” (line 287), and “dangerous” (line 271) to describe her experiences.

In the extract, Sue magnified the seizure dangers she has encountered, listing these in short succession. Sue emphasised the dramatic situations in which her seizures had taken place and the dangerous consequences of these. For example, “fits in the street” (lines 256 to 257), “middle of the road” (line 257), “in the bath and nearly drowned” (line 258), “had to be revived, you know give the kiss of life” (line 259 to 260), “pulled pans an top of me” (line 261), “even had an iron on top of me” (line 262).

Sue’s helplessness was evident in her apparent inability to make her situation any better. Indeed, the only (maladaptive) coping mechanism described was social dependency on her husband, “Without me husband ((laughs)), I never go anywhere else without him” (lines 251 to 252), “Never (0.4) cause I’m too afraid” (line 254). Sue helplessness was also apparent in her crediting her husband’s presence with reducing seizure occurrence and keeping her ‘safe’, as opposed to describing other (more positive) coping mechanisms, “I haven’t had any of them lately (be)cause (.) he’s always there ((laughing)) for me” (lines 266 to 268), “He won’t let me do the things that he finds dangerous” (line 270 to 271), “anything that he thinks I might endanger myself with” (lines 275 to 276).

Sue demonstrated that she ruminated on the bad possibilities of seizure occurrence. Sue had evidently given a good deal of thought to the negative aspects of her seizures. For example, Sue described being “too afraid” (line 254) and “frightened” (line 256) before she described the dramatic situations in which her seizures had taken place and the consequences of these.

Similarly, Sue appeared to ruminate on the negative aspects of her seizures to such an extent that she anticipated bad possibilities. For example, in relation to undertaking household tasks, Sue anticipated that she “would worry” (line 284) if she was able to carry out the tasks, “I would (1.3), if I were worrying, if I was erm able to do them” (lines 287 to 288). In addition, that she was now “too afraid” (line 254) and “frightened” (line 256) to go out on her own (without her husband).

Extract 3i:

247 D: Mhmh
248 P: So I'm lucky really, cause it's the only place
249 I ever go
250 D: Mh,
251 P: Without me husband ((laughs)), I never
252 go anywhere else without him.
253 D: Mh,
254 P: Never (0.4) cause I'm too afraid.
255 D: Mhmh
256 P: I'm frightened because I've had fits in the
257 street I've had them in the middle of the road,
258 I've had them in the bath and nearly drowned.
259 I had to be revived, you know give the kiss of
260 life, when er the bath. I've had them all over.
261 I've pulled pans an top of me,
262 I've, I've even had an iron on top of me.
263 (1.9) But this is when I were having a lot, I were
264 having at ten at a time, in a day.
265 D: Hm;
266 P: One time (0.8) but (.) I haven't had any of them
267 lately (be)cause (.) he's always there
268 ((laughing)) for me.
269 D: Mh,
270 P: He won't let me do the things that
271 he finds dangerous.
272 D: Mh,
273 (-)
274 P: Like he won't, he won't let me use pans or,
275 or boil a kettle, or or anything that he thinks
276 I might endanger myself with.
277 D: Mh,
278 P: I don't iron, because I've got arthritis as well
279 (-)
280 D: Hm mh
281 (-)
282 P: So, erm, there's none
283 of them (--) things around me any more.
284 But I would worry if it was.
285 D: Hm;
286 (-)
287 P: You know if, I would (1.3), if I were worrying,
288 if I was erm able to do them.
289 (-)

Another example of how someone with PNES (Betty) used a 'spontaneous seizure-related third party reference' to 'catastrophise' their experience is presented below in extract 3j.

In the account, Betty described experiencing "quite a few" (line 385) seizures at work, "a few" (line 386) at home, "quite a lot" (line 390) at a club across the street from where she lives, but as "just" (line 390) having "the odd one in d street" (line 391).

However, in her account Betty magnified the possibility of having a seizure in public (for example, in the "the street"). Betty amplified the possibility of "people" (line 394 and 401), specifically "strangers" (lines 395 and 397) seeing her have a seizure; "to see me" (line 395), "looking" (lines 397 and 400), and "staring" (line 401). Betty talked about this possibility in considerable detail and her account was littered with the anticipation of this (bad) possibility, "things happening" (line 394) and "I don't want" (lines 394 to 395, and lines 396, 397, 400, and 401).

Betty ruminated about the possibility of others ('strangers') witnessing her having a seizure to such an extent that she reported she does not, "really do anything anymore" (lines 392 to 393). Indeed, Betty appeared to have thought about this possibility to such an extent that she reported how she would react in the "strangers" place, "and if I saw someone, you'd be stood there looking" (lines 396 to 397).

Betty reported that the possibility of others ('strangers') witnessing her have a seizure was beyond her control and that she avoided activities ("don't really do anything anymore", lines 392 to 393) and going out in public ("So I (-) I jus (-) rather not give em the opportunity", lines 405 to 406). Betty, appeared helpless to make the situation any easier or better for herself, and her resulting negative 'mental set' was made clear, "me, me self I'm scared" (line 393).

Extract 3j

383 D: Mh,
384 (--)
385 P: (But) (-) I've had quite a few at work
386 (2.4) (and) I've had a few at home
387 (---) and as I say there was a local club
388 across from us, (--) is it's (bang) across
389 the road, and I used to work there as well.
390 So I had quite a lot there. (1.5) And I've just
391 had the odd one in d street, but apart
392 from that I don't really do anything
393 anymore (1.3). Because me, me self I'm scared
394 things happening where other people, I don't
395 want strangers to see me, and that's just
396 my personal opinion, I don't want,
397 I don't want strangers looking. I know if,
398 if it weren't me,
399 and if I saw someone, you'd be stood there
400 looking, and I don't want that,
401 I don't want people staring at me.
402 (1.7)
403 D: Mhh
404 (1.0)
405 P: So I (-) I jus (-) rather not give em the
406 opportunity.
407 (4.5)

An additional example of a 'spontaneous seizure-related third party reference' in which the patient 'catastrophised' their experience is presented in the Appendix (see Appendix, extract 2). The excerpt was taken from an interview with Laura who has PNES.

For the purpose of comparison, a 'seizure-related third party reference' to a 'partner' in which the patient neither 'catastrophised' nor 'normalised' their experience is presented in the Appendix (see Appendix, extract 5).

2.4 Coding procedure

The final coding frame used in the analysis is presented in the Appendix, figure 3.

The coding process began by identifying all 'seizure and non-seizure third party references' in the data. This was done by careful examination of transcripts and review of the video records. During this process, several passes of the data were made. The data was repeatedly analysed in its entirety until no additional 'seizure and non-seizure third party references' could be identified.

Thereafter, all 'seizure and non-seizure third party references' were scrutinised to determine how many of these could be classified as 'seizure-related third party references'. All 'non-seizure third party references' were excluded from further analysis.

The 'seizure-related third party references' identified in the data were analysed to see whether these were spontaneously made (volunteered) by patients or prompted by the interviewer (doctor). 'Seizure-related third party references' that were spontaneously made (volunteered) by patients were classified as 'spontaneous seizure-related third party references'. Those prompted by the interviewer (doctor) were labelled 'prompted seizure-related third party references'.

Following this step, all 'seizure-related third party references' were analysed to determine to whom the third party referred. All 'seizure-related third party references' identified in the data were analysed and the references were classified as falling into one of eight mutually exclusive relationship categories; 'partner', 'family members', 'friends and acquaintances', 'medical', 'employment', 'other institutional', 'unknown others' or 'unknown'.

Finally, the 'seizure-related third party references' identified in the data were used as points of reference to identify accounts in which patients 'catastrophised' or 'normalised' their experiences or whether the reference served neither purpose. During this process, all of the data (all of the consultations in their entirety) were repeatedly analysed.

As defined and stipulated in the coding frame, 'seizure-related third party references' used in accounts that 'catastrophised' or 'normalised' the patient's experience were identified. These were labelled as 'catastrophising - seizure-related third party references' or 'normalising - seizure-related third party references'.

After no more 'catastrophising - seizure-related third party references' or 'normalising - seizure-related third party references' could be identified in the data, these were examined to determine if the patient had spontaneously made (volunteered) the 'seizure-related third party reference' used in the account, or whether the interviewer (doctor) had prompted the patient to discuss a third party.

If the patient spontaneously referenced a 'seizure-related third party' in the course of a 'catastrophising' or 'normalising' account, these were labelled 'normalising - spontaneous - seizure-related third party references' or 'catastrophising - spontaneous - seizure-related third party references'. If the doctor was observed to prompt the patient to discuss a third party, and in responding to this request the patient referenced a 'seizure-related third party' in an account in which they 'catastrophised' or 'normalised' their experience, these were labelled as 'normalising – prompted - seizure-related third party references' or 'catastrophising – prompted - seizure-related third party references'.

Throughout the coding process, data analysis sessions were held with thesis supervisors (PD, MR, TW) to ensure the inter-subjective communicability of code definitions and the exclusivity of categorical codes. A selection of all the codes used in the analysis and how these were applied to the data were checked with supervisors during the course of these sessions. In addition, cases of uncertainty were raised in these sessions and the data in question collectively analysed to help ensure the optimal application of codes.

After the coding process was complete, the author was made aware of patient diagnosis. The codes identified in the data were then attributed to patients with PNES or patients with epilepsy.

2.5 Statistical methods

The length of interviews, gender (male/female) and age (years) of participants, the duration of patient's seizures (years), the frequency of patient's seizures (per month), the number of emergency admissions with seizures per participant and patients current AED use were assessed to determine any differences between diagnostic groups (participants with PNES and participants with epilepsy). Differences between the linguistic abilities (using the results of the Graded Naming Test (McKenna and Warrington, 1983) and the Test for Reception of Grammar (Bishop, 2003)), and anxiety, trauma and depression levels (using the results of the Anxiety and Depression Scale (HADS) (Zigmond and Snaith, 1983) and the Trauma History Questionnaire (THQ) (Green, 1996)) of the two patient groups were tested. Clinical and demographic differences between the two patient groups were explored using t-tests (for interval and ordinal data) and Fisher's Exact Tests (for nominal and categorical data).

For content analysis results, the Mann-Whitney U test was used to examine the statistical significance of between-group differences. In these analyses, ordinal data pertaining to the number of codes identified (for any one given code presented in the final coding frame) were classified as dependent (response) variables and patient diagnoses were classified as independent (predictor) variables (consisting of two categorical independent (nominal-dichotomous) groups, patients with epilepsy and patients with PNES).

An odds-ratio (OR) was calculated in two cases (during this final phase of statistical analysis all 'seizure-related third party references' that neither 'catastrophised' nor 'normalised' the patient's experience were disregarded). Fisher's Exact test was calculated alongside the OR's to examine statistical significance.

For the first OR calculation, the 20 interviews (consultations) used in the study were separated into two dichotomous (binary) categories, those that contained at least one 'catastrophising - seizure-related third party reference' and those that did not contain any 'catastrophising - seizure-related third party references' (total cases for both categories = 20). These were then classified (into two dichotomous (binary) categories) as made (or not made) in interviews with patients diagnosed with either epilepsy or PNES (total cases for both categories

= 20). In this model, the dependent (response) variable was the number of consultations that contained 'catastrophising - seizure-related third party references' (those that contained at least one 'catastrophising - seizure-related third party reference' and those that did not contain any 'catastrophising - seizure-related third party references'). The independent (predictor) variable was patient diagnosis (whether the patient was diagnosed with epilepsy or PNES). Please see the 2x2 contingency table in the results section (table 6).

In the second OR calculation, exactly the same process was followed using a different dependent (response) variable: the number of consultations in which at least one 'normalising - seizure-related third party reference' was or was not made (total cases = 20). Please see the 2x2 contingency table in the results section (table 7).

In addition, the Phi coefficient was calculated to determine effect size. Effect size was interpreted as negligible when Phi was between .00 and .10, weak when Phi was between .10 and .20, moderate when Phi was between .20 and .40, relatively strong when Phi was between .40 and .60, strong when Phi was between .60 and .80 and very strong when Phi was between .80 and 1.00 (Rea and Parker, 1992).

In all analyses of statistical significance, two-sided p-values of <0.05 were considered significant.

None of the statistical analyses described in this study were adjusted for clinical and demographic differences between the two patient groups. However, statistical (content analysis) results were considered in light of any clinical and demographic differences identified between the two patient groups (see Limitations).

Given that only one coder (the author) coded data, no formal (statistical) application of inter-coder reliability was applied. However, as described earlier, the development and application of codes used in this analysis was overseen by specialists in medical communication (PD, TW, MR). In addition, several passes of the data were made during the coding process to ensure identification of and correct categorisation of codes. Finally, the coder (author) was blinded to participant diagnosis during the coding phase of the research.

3. Results

3.1 Clinical and demographic features of patient groups

Clinical assessment of video-EEG recordings and review of patients clinical records (as described in the Methods section) by neurologists not involved in the study revealed that seven of the 20 patients who had given written informed consent to participate had epilepsy and 13 had PNES. The ratio of participants taking part in the study and diagnosed with epilepsy (35%) and PNES (65%) is typical of patients admitted to Sheffield Royal Hallamshire Neurology unit for monitoring and assessment.

Consistent with typical demographic findings (Reuber, 2008), patients with epilepsy were significantly older than patients with PNES and the proportion of females was significantly greater in the PNES group. Similarly, patients in the PNES group reported more traumatic experiences, and had higher mean anxiety and depression levels than the patients with epilepsy. Whereas no patients in the epilepsy group achieved the 'caseness' level on the HADS, in the PNES group, six patients scored at the 'caseness' level for anxiety and four for depression. The 'caseness' level describes cut-off points for anxiety or depression; this was defined as 8/21 for anxiety or depression (Bjelland et al, 2002).

The interviews lasted a median of 25 minutes each (range 16-46 minutes), with no statistical difference between PNES and epilepsy samples ($p=0.895$). Clinical and demographic differences between the two patient groups are summarised below in table 1.

Table 1: Clinical and demographic features of patients with PNES and epilepsy

	Epilepsy group (n = 7)	PNES group (n = 13)	Difference
Female gender	28.6%	84.6%	p=0.022
Age (years)	46 (35–67) ^a	32 (23–55) ^a	p=0.019
Duration (years)	17 (2–38) ^a	8 (0.5–17) ^a	n.s.
Frequency per month	24 (1–300)	14 (0.5–120)	n.s.
Emergency admissions with seizures	71.4%	84.6%	n.s.
Current AED use	71.4%	61.5%	n.s.
Graded Naming Test score	17 (14–21)	16 (8–23)	n.s.
Test for Reception of Grammar v. 2	17 (15–20) ^a	19 (12–20) ^a	n.s.
Hospital Anxiety and Depression score			
Anxiety	6 (3–9) ^a	10 (1–16) ^a	p=0.043
Depression	3 (1–7)	9 (1–12)	p=0.005
Trauma History Questionnaire score			
Physical and sexual events	0 (0–1) ^a	2 (0–12) ^a	p=0.007
Total events	3 (0–5) ^a	6 (1–25) ^a	p=0.028

^a Median (range)

3.2 Third party references

A total of 536 ‘seizure and non-seizure-related third party references’ were identified in the data. Twenty-six (4.9%) of these were unconnected with patients’ seizure experiences or discussion of their seizure condition and were subsequently excluded from further analysis.

A total of 510 ‘seizure-related third party references’ remained for analysis. Of these, 348 (68.2%) references were made by participants with PNES (mean 26.77 per interview, SD = 12.37) and 162 (31.8%) references were made by participants with epilepsy (mean 23.14 per interview, SD = 13.37). The mean number of references made in epilepsy or PNES encounters did not differ significantly (p0.588).

3.2.1 ‘Spontaneous seizure-related third party references’

Of the 510 ‘seizure-related third party references’ identified in the data, 85.3% (n=435) were classified as spontaneous and unprompted. Of these 435 ‘spontaneous seizure-related third party references’, 287 (66%) were made by participants with PNES (mean 22.07 per interview, SD = 10.89) and 148 (34%) were made by participants with epilepsy (mean 21.14 per interview, SD = 14.51). Differences in number of spontaneous third party references made by diagnostic groups did not prove statistically significant (p0.938).

3.2.2 'Prompted seizure-related third party references'

Of the 510 'seizure-related third party references' identified, 14.7% (75) were prompted by the interviewer. Of these, 61 (81%) were made by participants with PNES (mean 4.69 per interview, SD = 2.95) and 14 (19%) were made by participants with epilepsy (mean 2 per interview, SD = 2.65). The difference between the numbers of prompted third party references by diagnostic group proved statistically significant ($p=0.022$).

Table 2 below details group differences between the number and type (all, spontaneous and prompted) of 'seizure-related third party references' made by patients with PNES and patients with epilepsy.

Table 2: Group differences in the number and type of third party references made by patients with PNES and patients with epilepsy

Variable	N =	PNES N=	PNES Mean	PNES SD	EPS N=	EPS Mean	EPS SD	Mann - Whitney U test *
'Seizure-related third party references' (all)	510	348	26.77	12.37	162	23.14	13.37	$p=0.588$
'Spontaneous seizure-related third party references'	435	287	22.07	10.89	148	21.14	14.51	$p=0.938$
'Prompted seizure-related third party references'	75	61	4.69	2.95	14	2	2.65	$p=0.022$

*(Two-tailed)

3.2.3 'Seizure-related third party references' – relationship to the patient

Of the 510 'seizure-related third party references' in the data, 62 (12.1%) were made to 'partners', 79 (15.4%) to other 'family' members, 51 (10%) to 'friends and acquaintances', 179 (35.1%) to ('medical') healthcare professionals, 14 (3.3%) to 'other institutional' staff, 34 (6.7%) to ('employment') people in the workplace, and 91 (17.8%) to 'other unknown' or 'unknown' third parties. There were no significant differences in the distribution of 'seizure-related third party reference' relationship categories between patients with PNES and those with epilepsy. These results are summarised in table 3, below.

Table 3: Analysis of patient-third party reference relationship categories by diagnostic group

Relationship	N =	PNES N=	PNES Mean	PNES SD	EPS N=	EPS Mean	EPS SD	Mann - Whitney U test*
Family member	79	59	4.46	4.41	20	2.86	1.07	p=0.588
Partner	62	37	2.85	3.67	25	3.57	2.88	p=0.351
Friends and acquaintances	51	29	2.15	1.34	22	3.29	2.43	p=0.393
'Socially intimate' references^	192	125	9.46	6.37	67	9.71	3.86	p=0.699
Others unknown	89	65	4.85	3.41	24	3.43	2.82	p=0.393
Medical	176	119	9.15	5.77	57	8.14	8.07	p=0.438
Other institutional	17	12	0.92	1.61	5	0.71	0.95	p=0.877
Employment	34	25	1.92	1.89	9	1.29	1.25	p=0.588
Unknown	2	2	NA	NA	0	NA	NA	NA

^ Sum total of family member, partner and friends and acquaintance references.

*(Two-tailed)

3.2.4 'Normalising - seizure-related third party references'

Participants with epilepsy were significantly more likely to reference 'seizure-related third party references' in accounts that 'normalised' their experiences compared to participants with PNES (p0.019). A total of 25 'normalising - seizure-related third party references' were identified in the data. Of these, 84% (21, mean 3 per interview, SD = 2.4495) were made by participants with epilepsy and 16% (4, mean 0.3077 per interview, SD = 0.6304) were made by people with PNES.

3.2.5 'Normalising - spontaneous - seizure-related third party references'

A total of 21 'normalising - spontaneous - seizure-related third party references' were identified in the data. Of these, 17 were made by participants with epilepsy (mean 2.4286 per interview, SD = 2.0702) and 4 were made by participants with PNES (mean 0.3077 per interview, SD = 0.6304). Participants with epilepsy were significantly more likely to 'spontaneously' use 'seizure-related third party references' in accounts that 'normalised' their experiences compared to participants with PNES (p0.030).

3.2.6 'Normalising - prompted - seizure-related third party references'

Only four 'normalising - prompted - seizure-related third party references' were identified in the data, all of which were made by participants with epilepsy. Diagnostic differentiation did not prove statistically significant ($p=0.311$).

Table 4, below, details group differences between the number of 'normalising - seizure-related third party references' made by patients with PNES and epilepsy.

Table 4: Group differences in the number of normalising third party references made by patients with PNES and epilepsy

Variable	N =	PNES N=	PNES Mean	PNES SD	EPS N=	EPS Mean	EPS SD	Mann - Whitney U test*
'Normalising - seizure-related third party references'	25	4	0.3	0.63	21	3	2.45	$p=0.019$
'Normalising - spontaneous - seizure-related third party references'	21	4	0.31	0.63	17	2.43	2.07	$p=0.030$
'Normalising - prompted - seizure-related third party references'	4	0	0	0	4	0.57	0.98	$p=0.311$

*(Two-tailed)

3.2.7 'Catastrophising - seizure-related third party references'

Participants with PNES were significantly more likely to reference a 'seizure-related third party' in accounts in which they 'catastrophised' their experiences compared to participants with epilepsy ($p<0.001$). 54 'catastrophising - seizure-related third party references' were identified in the data. Of these, 51 (mean 3.6923 per interview, SD = 2.7804) were made by participants with PNES and 3 (mean 0.4286 per interview, SD = 1.1339) were made by participants with epilepsy. Participants with PNES made 94% of all the 'catastrophising - seizure-related third party references' in the data. Notably, the 3 'catastrophising - seizure-related third party references' made by participants with epilepsy were all made by one female participant.

3.2.8 ‘Catastrophising - spontaneous - seizure-related third party references’

Participants with PNES were significantly more likely to ‘spontaneously’ reference a ‘seizure-related third party’ in accounts that ‘catastrophised’ their experiences compared to participants with epilepsy (p0.005). 50 ‘catastrophising - spontaneous - seizure-related third party references’ were identified in the data. Of these, 47 were made by participants with PNES (mean 3.6154 per interview, SD = 2.7245) and three were made by participants with epilepsy (mean 0.4286 per interview, SD = 1.1339).

3.2.9 ‘Catastrophising – prompted - seizure-related third party references’

Only four ‘catastrophising – prompted - seizure-related third party references’ were identified in the data, all of which were made by participants with PNES. Diagnostic differentiation did not prove statistically significant (p0.275).

Table 5, below, details group differences in the number of ‘catastrophising - seizure-related third party references’ made by patients with PNES and epilepsy.

Table 5: Differences in the number of ‘catastrophising - seizure-related third party references’ made by patients with PNES and epilepsy

Variable	N	PNES N=	PNES Mean	PNES SD	EPS N=	EPS Mean	EPS SD	Mann - Whitney U test*
‘Catastrophising - seizure-related third party references’	54	51	3.69	2.78	3	0.43	1.13	p<0.001
‘Catastrophising - spontaneous - seizure-related third party references’	50	47	3.62	2.73	3	0.43	1.13	p=0.005
‘Catastrophising – prompted - seizure-related third party references’	4	4	0.31	0.48	0	0	0	p=0.275

*(Two-tailed)

3.2.10 Diagnostic differentiation: ‘Seizure-related third party references’ used in ‘catastrophising’ and ‘normalising’ accounts

As detailed below in table 6, at least one ‘catastrophising - seizure-related third party reference’ was made in 12/13 (92.3%) of encounters with patients with PNES and 1/7 (14.3%) of encounters with patients with epilepsy (p=0.001). An OR of 72 (95% CI 3.81 to 1361.94) indicated strong positive association; and suggested that participants with PNES were 72 times more likely to use at least one ‘catastrophising - seizure-related third party reference’ in their conversation with the doctor compared to participants with epilepsy. In addition, a strong effect size was observed (Phi coefficient +0.78).

Table 6: ‘Catastrophising seizure-related third party references’ used in consultations with people with epilepsy and people with PNES

	No catastrophising ‘third party’ reference was made	At least one catastrophising ‘third party’ reference was made	Total
PNES	1	12	13
EPS	6	1	7
Total	7	13	20

As detailed below in table 7, at least one ‘normalising - seizure-related third party reference’ was made in 2/13 (15.4%) of encounters with patients with PNES and 6/7 (85.7%) of encounters with patients with epilepsy (p=0.004). An OR of 33 (95% CI 2.45 to 443.61) indicated moderate to strong positive association; and suggested that participants with epilepsy were 33 times more likely to use at least one ‘normalising - seizure-related third party reference’ in their conversation with the doctor compared to participants with PNES. In addition, a relatively strong effect size was observed (Phi coefficient +0.68).

Table 7: ‘Normalising seizure-related third party references’ used in consultations with people with epilepsy and people with PNES

	No normalising ‘third party’ reference was made	At least one normalising ‘third party’ reference was made	Total
EPS	1	6	7
PNES	11	2	13
Total	12	8	20

4. Discussion

4.1 Third party references

Most of the third party references identified in the data (over 95%) were made in relation to patients' seizure experiences or their seizure condition (and were classified as 'seizure-related third party references').

Significant differences in how patients with epilepsy or patients with PNES referred to third parties were observed. There were no significant differences between the two diagnostic groups in terms of the total number of 'seizure-related third party references' or references made 'spontaneously' by patients without prompting from the doctor. However, patients with PNES were significantly more likely to be prompted to tell doctors what others have told them about their seizures or their seizure condition.

The finding that people with PNES need to be prompted to discuss or invoke 'third party references' in relation to seizure episodes or their seizure condition compared to people with epilepsy is consistent with the literature.

Previous research has suggested that patients with PNES tend to need more prompting to describe their seizure symptoms and recollections compared to patients with epilepsy. As identified in the literature review (chapter two), authors have reported that people with PNES typically avoid, and are less able to focus on, seizure episode descriptions; often in spite of considerable prompting from doctors. Authors have observed that people with PNES do not ordinarily volunteer or initiate seizures as a topic of discussion; they typically resist discussing subjective seizure symptoms, resist elaborating their accounts of phases of reduced self-control, they find it difficult to focus on seizure experiences, specific seizure episodes and trajectories, and require considerable prompting to do so compared to people with epilepsy (Schwabe et al, 2008; Schwabe, Howell and Reuber, 2007 and Plug, Sharrack and Reuber, 2009a). In addition, four of the DSA items used in Reuber et al's (2009) study featured prompting as a defining characteristic of PNES patient talk. All of these items (items 1, 2, 4 and 6) proved significant for correct classification for one of the two raters in the study.

The finding that people with PNES need to be prompted to discuss or invoke 'third party references' in relation to seizure episodes or their seizure condition compared to people with epilepsy may reflect the psychopathology that underpins PNES.

Dissociation and avoidance behaviour are key psychopathological features of PNES (Frances, Baker and Appleton, 1999; Reuber et al, 2007; Griffith, Polles and Griffith, 1998 and Goldstein et al, 2000). PNES are usually interpreted as a manifestation of dissociative avoidance behaviour (Reuber, 2008 and Goldstein and Mellers, 2006). This interpretation is supported by studies based on self-report questionnaires, which have shown that patients with PNES have greater avoidance and dissociation tendencies than patients with epilepsy (Goldstien and Mellers, 2006; Kuyk et al, 1999 and Lawton, Baker and Brown, 2008). What is more, recent experimental work probing the neurobiological basis of PNES has provided further evidence for excessive (preconscious) avoidance tendencies to potentially threatening stimuli in patients with PNES (Bakvis et al, 2011).

The need for the doctor to be more active in interviews with PNES patients may be a consequence of the 'detailing block' and 'focusing resistance' typically exhibited by these patients when they describe their seizures. As Lacey, Cook and Salzberg (2007) have observed, patients with PNES may *"shift abruptly from one stance to the other ... [and that] ... For the doctor, the abrupt, marked shifts in stance of the patient with PNES, often within a single consultation, may be disconcerting"* (p492).

Doctors may have to do more work in their conversations with patients with PNES (and may be tempted to enquire about what other people have said about their seizures) to deal with the fact that the illness narratives of their patients (like those with other medically unexplained neurological symptoms) (Nettleton et al, 2005) are somewhat chaotic and incoherent. There are certainly instances in the data when the doctor appeared to use enquiries about third parties in order to 'go back' and explore clinical features of seizure descriptions and the trajectory of the condition by enquiring about the views of third parties.

Therefore, more prompting is likely to occur during interactions with PNES patients in comparison to epileptic patients, as doctors need to overcome PNES patients resistance and avoidance tendencies in order to 'take the history'.

4.2 'Seizure-related third party references' – relationship to the patient.

No significant differences were observed in the frequency of 'seizure-related third party references' used by patients with epilepsy and patients with PNES to reference their 'partner', 'family' members, 'friends and acquaintances' (or 'socially intimate' references), 'unknown others' or persons in 'medical', 'employment', or 'other institutions' in the data.

However, research findings from the wider literature suggest that relationship dynamics are an important distinguishing factor between PNES and epilepsy patient groups.

A number of studies have shown that family dysfunction, trauma and abuse are significantly greater in PNES populations than epilepsy populations and healthy controls (Alper et al, 1993; Griffith, Polles and Griffith, 1998; Krawetz et al, 2001 and Fisman et al, 2004). For example, research by Krawetz et al (2001) indicated greater family psychopathology and dysfunction among the families of PNES patients compared to epileptic patients. Diagnostically differential and statistically significant results using the McMaster Family Assessment Device (FAD) and the Beavers Self-Report Family Inventory (SFI) indicated greater communication difficulty, lower effective involvement, lower general functioning, and greater difficulty with conflict among PNES patients and their families compared to epilepsy patients and their families (Krawetz et al, 2001). Similarly, Moore et al (1994) observed that people with PNES perceived their families as displaying less support and commitment to each other compared to epileptic controls when measured against the Family Cohesion Scale (FCS).

Authors have also observed that people with PNES typically report feeling isolated and cite a loss of independence (Thompson's et al, 2009) and increased social dependence on others (Reuber, 2008) as a result of their seizure condition. Moreover, research has suggested that third parties may reinforce maladaptive behaviours in this group of seizure patients (Lesser, 2003).

It has also been reported that people with PNES may express doubt and uncertainty about others (third parties) and describe how they are doubted by others (including by medical care staff) (Thompson et al, 2009). Similarly, Plug, Sharrack and Reuber (2009c) observed that patients with PNES were more likely to express dissatisfaction with previous medical treatment compared to participants with epilepsy. In contrast, Reuber and Monzoni (2009) found that people with epilepsy sometimes supported factual accounts of seizure episodes with witness accounts and direct reported speech or thought, referencing family, friends or members of social networks to bolster narratives of positive coping styles.

Given this research base, exploration of third party reference use in this context (using relationship categories) was considered a worthwhile avenue of enquiry in the analysis. For example, participants with epilepsy may have been more inclined to reference partners and family members when they described their seizure experiences or condition compared to people with PNES. Alternatively, patients with PNES may have been more inclined to reference medical professionals when they described their seizure experiences or their seizure condition.

Unfortunately, due to the research design, the reason for referencing a 'seizure-related third-party' (other than 'catastrophising' or 'normalising') was not coded for in the analysis. As described in the methods section, the development of 'positive' or 'negative' coding categories was difficult, and tangible definitions were not forthcoming. It was not possible to develop mutually exclusive coding sub-categories from these concepts during development of the coding frame.

In addition, the analysis of 'seizure-related third party reference' relationship categories used in accounts in which patients 'catastrophised' or 'normalised' their seizure experiences was not possible. This was due to two main reasons. Firstly, the relatively small numbers of 'seizure-related third party references' in each relationship category identified, coupled with the comparatively small number of 'catastrophising – seizure-related third party references' and 'normalising – seizure-related third party references' identified in the data, meant that statistical analysis was not possible. Secondly, as described in the methods section, it was sometimes the case that more than one 'seizure-related

third party reference' was used in an account in which patients 'catastrophised' or 'normalised' their experiences. However, to avoid over-representation, these references were counted as a single display if used in the bounds of the same 'catastrophising' or 'normalising' account.

Nevertheless, given the differences between PNES and epilepsy patient relationships with others (third parties) identified in the literature, it is anticipated that differences between how and why these patients reference particular categories of third parties would be of interest in future studies, especially with regards to 'partner', 'family' and 'medical' references.

4.3 'Seizure-related third party references' used to 'catastrophise' and 'normalise'

The results presented in this study suggest that patients that use 'seizure-related third party references' in accounts in which they 'catastrophise' their experiences and their life with seizures are more likely to have PNES, whilst patients that use 'seizure-related third party references' in accounts in which they 'normalise' their experiences and their condition are more likely to have epilepsy.

Previous studies have hinted at the observation made here that compared to patients with epilepsy, patients with PNES have a tendency to 'catastrophise' in their interaction with the doctor. It has been shown that, unlike patients with epilepsy who focus on their seizure symptoms and subjective seizure experience, patients with PNES preferentially volunteer talk about negative aspects of their seizure disorder, such as the consequences of having seizures, the dangerous or embarrassing situations in which their seizures have occurred (Plug and Reuber, 2009 and Plug, Sharrack and Reuber, 2009a) and their dissatisfaction with previous treatment (Plug, Sharrack and Reuber, 2009c).

Despite the close alignment of these interactional features with displays of catastrophisation, no studies of catastrophisation in doctor-patient interviews

about seizures has previously been undertaken. Defined as a distinct construct comprising three correlating dimensions (reflection, helplessness and magnification) that result in an exaggerated negative 'mental set' (Sullivan et al, 2001), catastrophisation has been found to play an important role in medical illness and illness behaviour (Kirmayer and Looper, 2006). Most extensively applied to pain research, measures of catastrophisation have been shown to explain much of the variance of anticipation, perception and manifestation of pain severity (Sullivan, Bishop, and Pivik, 1995; Burton et al, 1995; Ploghaus et al, 1999; Sullivan et al, 2001; Smeets et al, 2006; Bartley and Rhudy, 2008 and Fabian et al, 2001). For instance, Burton et al (1995) found that catastrophisation explained 47% of variance predicting the development of an episode of acute pain in patients with chronic pain.

The finding that 'seizure-related third party references' used in accounts that 'catastrophise' seizure experiences are used much more commonly by patients with PNES than those with epilepsy (92.3% of patient's with PNES versus only 14.3% of patients with epilepsy used such references) is of considerable interest because, like the interactional manifestations of avoidance, it links patients' cognitions (as evidenced by their communication behaviour) to the likely underlying psychopathology of PNES.

Catastrophisation about benign physical symptoms (such as breathlessness) is a key cognitive feature of panic disorder (Hermans et al, 2010); the interactional manifestations of catastrophisation in panic disorder have been discussed in a detailed case study (Capps, Bruner and Ochs, 1995). There is also a recognised link between the tendency to catastrophise and somatoform disorders (Kirmayer, Robbins and Paris, 1994). In fact, it has been suggested that dysfunctional cognitions (specifically the tendency to catastrophise), should be included in the future diagnostic criteria for somatoform disorder in the DSM-V and ICD-11 (Löwe et al, 2008).

Despite being previously framed as a cognitive component of depression, recent research has indicated that catastrophisation is distinct from, and independent of its association with depression (Sullivan et al, 2001 and Martin et al, 1996). Nevertheless, catastrophisation has been shown to affect emotional functioning, and higher levels of anxiety and anger have been

observed in those who catastrophise (Sullivan, Bishop and Pivik, 1995 and Eccleston et al, 2004). Indeed, the patients with PNES described here self-reported higher anxiety scores than those with epilepsy. In addition, catastrophising has been shown to significantly contribute to the variance of emotional or psychological distress associated with pain experiences, even when controlling for the level of physical impairment or disease severity (Severeijns et al, 2001 and Fabian et al, 2011).

In pain patients, the likelihood of catastrophisation tendencies is associated with a positive history of abuse (Fillingham, Wilkinson, and Powell, 1999). In this patient group, catastrophising has also been strongly linked to insecure attachment (McWilliams and Asmundson, 2007), which, in turn, is an established long-term consequence of trauma and abuse (Stalker, Gebotys and Harper, 2005). The patients with PNES described here self-reported higher prevalence of trauma and abuse than those with epilepsy. Likewise, other authors have observed that the prevalence of trauma and abuse is much higher in PNES populations. For instance, a systematic review of the literature found that PNES samples showed very high rates of trauma (44-100%) and abuse (23-77%), which were some 15-40% higher than those found in healthy and epileptic control groups (Fizman et al, 2004). Catastrophisation tendencies have not been studied in the same way in patients with PNES but the links between PNES and a history of trauma, abuse, neglect in early life and subsequent insecure attachment are well established (Holman et al, 2008 and Reuber, 2009).

Catastrophisation has been conceptualised as a coping strategy in the pain literature (Keefe, Lefebvre and Smith, 1999). It may not be immediately apparent why patients would adopt a cognitive and communicational style characterised by catastrophisation as a 'coping technique', but it has been suggested that the fear-avoidance model may offer an explanation (Sullivan et al, 2001). In this model the fear of an adverse physical symptom (such as the anticipation of pain or seizures) leads to activity avoidance and heightens perceptions of disability (Vlaeyen et al, 1995). This model may apply in patients with PNES who have been shown to be significantly more likely to use (maladaptive) escape-avoidant coping strategies and significantly less likely to use (more effective) planful problem solving approaches to coping than people with epilepsy and healthy controls (Stone, Binzer and Sharpe 2004; Frances,

Baker and Appleton, 1999 and Goldstein et al, 2000). The fear-avoidance model also underpins a cognitive behavioural therapeutic approach that has proven effective for PNES (Goldstein et al, 2010).

Nevertheless, despite considerable links, it has been argued that catastrophising is not goal orientated or specific and should not, therefore, be conceived as a coping strategy (Haythornthwaite and Heinberg, 1999). However, Keefe, Lefebvre and Smith (1999) have pointed out that, despite being associated with negative outcomes, catastrophising does fit current definitions of coping; and research has demonstrated catastrophising to be significantly correlated with coping effectiveness (Rosenstiel and Keefe, 1983 and Keefe, Lefebvre and Smith, 1999). This has led theorists to suggest that catastrophisation may be best viewed from a distinct 'social' perspective. In this model, catastrophising appears to serve a communicative (social-behavioural) function as it maximizes the possibility that distress is managed socially rather than individually. It may lead to lower spousal expectations for patient participation in home, social, employment and vocational activities (Sullivan et al, 2001). In a study of pain coping strategies that predicted patients' and spouses' rating of patients' self-efficacy, Keefe, Lefebvre and Smith (1999) found increased patient catastrophisation to be associated with reduced involvement in day-to-day activities and decreased spousal perceptions of the patients ability to cope.

The lives of patients with PNES disorders (like those of other patients with somatoform disorders) often seem to involve a high degree of dependence (Kirmayer, Robbins, and Paris, 1994 and Kaplan and Sadock, 1998). For example, Thompson et al (2009) cite a loss of independence as a salient factor in a study exploring PNES patient accounts, and Reuber (2008) suggests that in chronic PNES cases 'dramatisation' may be rewarded by social and/or financial illness gain, in which unpleasant responsibilities may be passed on to others. Similarly, authors have observed that the behaviours of others (for example, family, friends and co-workers) may contribute to the maladaptive coping strategies observed in PNES patients (Frances et al, 1999; Stone, Binzer and Sharpe, 2004 and Lesser, 2003).

5. Limitations

The generalizability of findings from this study is limited in a number of respects. The findings are based on a relatively small sample, especially of patients with epilepsy. In addition, the secondary data used in this study forms part of a larger collection of data gathered by members of the 'Listening to people with seizures' project, hosted by the University of Sheffield. An opportunistic sampling method was used to collect this data and a third party (MR) obtained informed consent from participants. The number of patients that chose not to participate in the study (and the clinical and socio-demographic characteristics of these patients) was not recorded. There may have been differences between the patients that chose to participate in the study and those that did not. In addition, those that choose to participate may have varied their behaviour as a consequence of observation. Moreover, the Principal Investigator of the 'Listening to people with seizures' project (MR) selected the sample of consultations that were investigated in this study. As such, it is possible that selection bias occurred.

The consultations (interviews) examined in this study took place whilst patients were undergoing inpatient observation with video-EEG. In addition, the doctor involved in these encounters (MR), used the 'EpiLing' interview method to collect data. As discussed in chapter two, there are likely to be considerable differences between this method and the methods typically used by doctors to 'take the history' in conventional outpatient interactions. For example, use of the 'EpiLing' interview method limits the doctor's interactional contributions to a significant extent. Giving patients more time to develop and express their own experience narratives is likely to increase the occurrence of spontaneous patient talk (including spontaneous references to third parties). However, use of the 'EpiLing' interview method in these encounters did mean that there was a greater standardisation of consultation structure across the encounters than would be expected in a collection of conventional outpatient interactions. As such, the overall comparability of the medical encounters was enhanced. Nevertheless, the environment in which the consultations (interviews) were conducted and the ('EpiLing') method used to gather information does mean that these encounters may not replicate interactions which occur between doctors and patients in outpatient clinics. Likewise, that the findings described here may be different from those found in routine (outpatient) clinic encounters.

Despite employing a rigorous methodological approach to the development of coding schema and data coding it is acknowledged that inter-coder reliability was not calculated. Only one person (the author) coded the data. However, the development (the definition and application) of codes was discussed with thesis supervisors (PD, TW, MR) during regular data sessions. During the final coding procedure, thesis supervisors (PD, TW, MR) continued to check the application of codes at regular intervals and any cases of uncertainty were brought to their attention for collective analysis. In addition, several passes of the data were made during the coding process to help ensure the optimal identification and categorisation of codes.

However, it remains the case that there is always some degree of interpretation involved in a content analysis (as with many other forms of qualitative analysis). The degree of interpretation applied to data is likely to be wider (more of an issue) when the latent content as opposed to the manifest content of the data is examined (Hsieh and Shannon, 2005). For example, in the data presented here, identification of 'catastrophising' and 'normalising' displays was more complex and involved a greater degree of interpretation than the identification of, for example, 'seizure-related third party references'.

A number of clinical and demographic differences between diagnostic groups (patients with epilepsy and patients with PNES) were observed in this study. However, none of these differences were adjusted for in the statistical analyses. Having said this, no significant differences between PNES and epilepsy patient samples was observed with regard to the duration of the consultations, the number of years participants had experienced seizures, seizure frequency per month, the number of emergency admissions with seizures, current AED use, or participants linguistic abilities (as measured by the Graded Naming Test score, the Test for Reception of Grammar). Moreover, any clinical and demographic differences observed were consistent with these patient groups (Reuber, 2008). Participants with epilepsy were significantly older than participants with PNES, the proportion of females was significantly greater in the PNES group and PNES participants self-reported more traumatic events and higher levels of depression and anxiety than epileptic participants (as measured by the Hospital Anxiety and Depression Scale and Trauma History Questionnaire).

Finally, content analysis has been described as a deductive approach, in that it does not reveal the underlining reasons for the patterns observed (Berg, 1998). Similarly, while useful relationships and correlations are often observed when content analysis is used as the main method of investigation, there is an inability to assess causality. The proposed reasons why people with PNES and epilepsy referenced third parties differently in this study, although supported by findings from the wider literature, are hypothetical and need to be treated with caution.

6. Conclusion

Despite these limitations, this study suggests that, in addition to other previously described interactional and linguistic observations, there are significant differences in terms of how patients with epilepsy and patients PNES refer to third parties when they talk to a doctor about their seizures.

The findings from this study help to inform existing models of interactional criteria that help distinguish between the linguistic and communicative features of seizure descriptions by people with epilepsy and PNES. When doctors take the history from patients with PNES they be more inclined to prompt patients to discuss third parties, for example, to tell them what others have told the patient about their seizures. In addition, this research suggests that patients that use third party references to catastrophise their seizure experiences are more likely to have PNES and patients who use the same references to normalise their life with seizures are more likely to have epilepsy.

The close examination of doctor-patient encounters in this study may also help researchers and clinicians better understand how people with PNES and epilepsy experience and cope with a seizure disorder. This appears to be particularly true of patients with PNES, who were frequently observed to use third party references during accounts in which they catastrophised their seizure experiences. Examining the emotional and psychological insights associated with displays of 'catastrophisation' may help neurologists and psychologists provide more targeted support and treatment for people with PNES.

This study explored interactions in which a doctor and seizure patient was present. However, patients are routinely encouraged to bring a witness to their initial (diagnostic) seizure clinic appointment, if possible. In clinical encounters in which patients are not alone with their doctor, accompanying persons are often engaged in the conversation. However, clinical encounters in which patients are accompanied to visits have not been previously examined in a neurology outpatient or seizure clinic setting. In the next phase of this research project, the effect of companions in these encounters is examined.

However, before the next phase of empirical study commenced, the different theoretical perspectives of analysts and the methods used to examine accompanied interactions in other clinical settings needed to be assessed. Therefore, a comprehensive review of the accompanied patient literature is presented in the next chapter of this thesis.

**Chapter four: Accompanying persons in medical interactions -
a comprehensive review of the literature.**

1. Introduction

Sociologists have considered triadic interaction, or 'three-person association', since at least the time of Simmel (1902,1908). Translated by Wolff (1950), Simmel's commentary on the theoretical underpinnings of triadic interactions came to the fore in the mid-twentieth century. Laying the foundations for the study of nearly all triadic interaction analysis that followed, Simmel made a number of significant observations. The most important was that three-person associations reveal power relations and the emergence of a majority and hence form the cornerstone from which society as a whole, and socialisation, can be considered (Hill and McGrath, 2008).

Simmel (Wolff, 1950) observed that depending on the role the third party plays during the encounter, the addition of a third person to a dyadic (two person) encounter can significantly alter the functions of the group, and completely transform established dyadic communication patterns and alliances. Interpreting the work of Simmel (Wolff, 1950), Barone, Yoels and Clair (1999) suggested that this phenomenon was primarily due to three fundamental consequences of three party groups. Firstly, a dyadic encounter always loses intimacy when a third person is introduced, and solidarity is disturbed regardless of the strength of the triadic relationship. Secondly, a member of a triad finds it much easier to refrain from discourse and not to participate. Thirdly, the addition of a third member makes a majority possible and allows for the formation of alliances (or coalitions) that cannot be achieved in dyadic interactions.

Simmel (Wolff, 1950) suggested that the extent to which a third person can change the functions of the group depends on the role they play during the encounter. He identified three third party roles, '*mediator*', '*tertius gaudens*', and '*oppressor*'. As described by Coe and Prendergast (1985), the '*mediator*' can be likened to a diplomat, negotiating equally between the two other members. The '*tertius gaudens*' ('third who enjoys') is seen as an exploiter, taking advantage of dissention between the two other members and using this to their own advantage, and tipping the scales of power in their own favour. Finally, the

'oppressor' is described as evoking conflicts, and using a 'divide and conquer' technique to achieve their goals.

Empirical applications of Simmel's work soon followed Wolff's (1950) translation. Referred to as 'coalition theorists', the likes of Mills (1953, 1954), Bales and Borgatta (1955), Strodtbeck (1954), Torrance (1955), Caplow (1956, 1959), Vinacke and Arkoff (1957) and Vinacke (1959) devoted considerable time to the study of triadic interactions, and coalition formations in particular (Hill and McGrath, 2008). Using quantitative measures of rates of interaction, for example Bales' (1950) Interactive Process Analysis (IPA), the researchers sought to empirically investigate the roles and outcomes of three party group members in a variety of (predominantly experimental) settings. Two of these theorists, Mills (1953, 1954) and Caplow (1956, 1959) were particularly influential.

Mills (1953, 1954) verified Simmel's (Wolff, 1950) proposition that members of a triad tend to separate into a pair (dyad) and the remaining other, and that the pair (dyad) is usually composed of the two most active participants, with the least active member isolated (Adelman, Greene and Charon, 1987). Mills (1953) identified the different power relations that exist between the two most active members in triadic coalitions. Caplow (1956, 1959, 1968) went on to identify eight different types of coalitions that could form in different triadic interactions, dependent on the initial power base of the members. In his analysis, Caplow (1956, 1959) anticipated that where initial power bases of members differed, coalitions (alliances to achieve a desired goal) formed at the expense of a passive or active 'other' as members sought to increase their power base and control the interaction (Adelman, Greene and Charon, 1987).

Following Caplow's proposition (1956, 1959), Thibaut and Kelley (1959) observed that coalitions (power relations) did not always form in triads where there was unanimous agreement on the desirability of goals (outcomes). The authors proposed that the formation of coalitions in triadic interactions are dependent on the initial power base of individual members and that the distribution of power in the triad can predict, with some success, the type of coalitions (alliances) that inevitably formed.

Building on Simmel's (Wolff, 1950) earlier propositions, Mills (1953, 1954) and Caplow's (1956, 1959) work (alongside others) was subsequently expanded into economics, negotiation models, and influenced the development of game theory. Developments in the study of triadic communication, spurred by the work of Mills and Caplow, caused a surge of interest in communication tactics during the 1970s. Broadly labelled 'game theorists', researchers began turning their attention toward decision-making behaviours, and like those that preceded them, used coalition formation in triad interactions as their main point of reference. Caplow's 1968 synthesis of his work on triadic interactions has been credited as strongly influencing the social science literature on triadic interactions that emerged during the 1960s and 1970s (Hill and McGrath, 2008).

During the mid 1970's, a second stream of study into triadic and small group interaction began to emerge in the social sciences. In contrast to coalition theorists' preoccupation with quantitative study, numerous micro-behavioural studies were undertaken that focussed on behavioural patterns of communication in triadic and other small group interactions. The rise of microanalysis, made popular by figures such as Goffman (1959, 1961, 1967) and Garfinkel (1967), turned attention to the organisation, form, order and content of social interactions, and the rules of engagement actors employed in social exchanges. In a similar spirit, Goffman's later work added momentum to the field with his discussion of participation frameworks and alignments; his central contribution being that a participation framework encompasses all interactional stances and footings (alignments) taken by social actors within the course of any given social interaction to 'realign' and 'reframe' their participation (Goffman 1981, 1983).

Triadic research also spread in the field of psychiatry. Building on studies dating from at least the 1960's (for example, Weakland's (1960) exploration of psychotherapeutic family therapy encounters), a number of studies investigating the interpersonal relationships of mental health patients in triadic and small group contexts materialised.

From the 1980's onwards, researchers began to apply the theories and methods of triadic interaction research to specific settings. A focus on triadic interaction became more commonplace in family studies (including couple or family therapy), doctor-patient relationships and conflict resolution (Hill and McGrath, 2008).

However, of all the disciplines where the study of triadic interaction has been applied, perhaps the most prominent is the field of medicine. Commonly referring to 'accompanied interactions', these studies explore accompanied patients in triadic interactions and in encounters where more than one accompanying person may be present. Following methodological traditions proposed by coalition theorists and microanalysts, triadic doctor-patient interactions have been studied using three broadly defined methods: process analysis, micro-analysis, and (mixed) methods combining elements of the two (Coe and Prendergast, 1985).

1.1 Aims and objectives

The main aim of this review was to explore the methods used by researchers to analyse accompanied patient interactions. Within this, a particular objective was to examine and assess the methods used by researchers to analyse observational data. The overview of these methods was intended to guide the analytical approach to the seizure clinic data studied in this project.

Whilst no previous studies have examined accompanied encounters in a seizure clinic setting, the effects of companions on interactions between patients and doctors have been described in observational studies in other areas of medicine. A further aim of this review was to summarise the findings of these studies and to explore the extent to which studies of accompanied interactions in different clinical areas are comparable. To this end, the rates of accompanied and unaccompanied visits described in different studies and the clinical and demographic characteristics of patients and companions were examined. This part of the review was intended to determine to what extent the findings from the seizure clinic could be compared to those of studies carried out in different clinical settings.

2. Methods

2.1 Search strategy

A flow chart summarising the search strategy used in this review, the inclusion and exclusion criteria that were applied, and the number of studies identified at each stage of the search can be found in the Appendix (see Appendix, figure 4).

The (ISI) Web of Knowledge database was selected as the sole database to be searched for this review. The (ISI) Web of Knowledge database combines a wide range of individual databases; the Science Citation Index Expanded, Social Sciences Citation Index, Arts & Humanities Citation Index, Conference Proceedings Citation Index - Science, Conference Proceedings Citation Index - Social Science & Humanities, Book Citation Index - Science, Book Citation Index - Social Sciences & Humanities, Current Chemical Reactions, Index Chemicus, BIOSIS citation index, Current contents connect, Derwent innovations index, Data citation index, Medline, and Journal citation reports. It incorporates key social science and medical databases and covers over 12,000 international and regional journals in every area of the social sciences, natural sciences and arts and humanities (Vesta, 2012).

A scoping review was conducted to determine the most appropriate search terms to use. This resulted in a search strategy consisting of the labels: accompanied, accompany (accomp*), companion, companions (companion*), family, family's, families (famil*), third party, third parties (third part*), triad, triads and triadic (triad*), in conjunction with at least one of the words, doctor, doctors (doctor*), medical (medical), consultation, consultations (consultation*), visit and visits (visit*). Finally, as used in the previous literature review search (see chapter two), 'discourse associated' descriptors were incorporated in the search set (communicat*, conversation*, interactional, description*, talk*, or discourse).

The full search set used was: accomp* OR companion* OR famil* OR third part* OR triad* AND doctor* OR medical* OR consultation* OR visit* AND communicat* OR conversation* OR interactional OR description* OR talk* OR discourse

The (ISI) Web of Knowledge is a citation and abstract search engine. As with other large database search engines (for example, Scopus and PubMed), it is not possible to search the full text of articles using the (ISI) Web of Knowledge. Therefore, title, abstract and keyword searches were conducted. By default, a topical area search in the (ISI) Web of Knowledge includes a search of the title, abstract and keywords of journal articles. The search was refined by selecting the 'English language' search option and the 'article' search option (only journal 'articles' were searched, 'conference proceedings' were excluded from the search). In the search, no criteria were applied to limit the date articles were published (the 'timespan – all years' search option was chosen). Finally, the 'all databases' search option was selected.

This search (initially performed in May 2011 and updated in July 2012) resulted in 275 articles identified for potential inclusion in the review. The abstracts of these articles were searched to assess whether studies met inclusion or exclusion criteria (presented below). If it was apparent that studies did not meet inclusion criteria, they were excluded at this stage. If studies appeared to meet inclusion criteria or there was uncertainty as to whether inclusion criteria were met, then full text articles were downloaded and assessed. The bibliography and reference sections of articles identified for inclusion were searched to identify applicable studies not already identified.

2.1.1 Inclusion criteria

Interactions had to take place in a medical setting. Studies were included if one or more companions accompanied patients to the visit. A companion was defined a friend, family relation, friend, caregiver or neighbour or another within the patient's 'social circle'. No other eligibility criteria were applied regarding study methodology, patient or companion clinical and socio-demographic characteristics, or the number of study participants.

2.1.2 Exclusion criteria

Interactions that exclusively consisted of companions that were outside of the patient's 'social circle', for example, interpreters or allied health and social care professionals (e.g. social workers) were excluded.

Given that the motivation for this review was to inform the subsequent analysis and contextualisation of encounters in interactions in the setting of a neurological outpatient clinic, studies of accompanied interactions in very different medical settings (such as psychiatry, psychology, couple or family therapy, emergency room, and end of life (palliative care) settings) were also excluded. Further reasons for these exclusions are described below.

Accompanied interactions that take place in couple or family therapy settings are ordinarily composed of more than one patient. That is, a companion does not usually accompany the patient; rather, multiple patients (or clients) attend consultations in these settings. These interactions are somewhat unique in this respect.

Similarly, the Royal College of Psychiatrists considers psychiatry 'a unique branch of medicine' (Branton, 2012). Authors have observed that there are specific aspects and challenges of communicating with patients in psychiatry and that doctor-patient communication can be complicated by patient symptoms and therapeutic situations in this setting (Priebe et al, 2011). For example, patient involvement in psychiatric encounters may not be voluntary and patient consent is not necessarily required before consultations are conducted or treatment is administered. The perceived uniqueness of psychiatry as a medical discipline has led practitioners in the field to call for a unique set of ethics to govern clinicians practicing in this setting (Radden, 2002).

Interactions that take place in emergency room (A&E) settings were also considered as constituting distinct doctor-patient interactions. Authors have observed that the acute nature of emergency medicine means that there are unique communication challenges in this setting (Knopp et al, 1996). Similarly, the conversations taking place in end of life care settings and the communication practices of healthcare professionals in these settings have been observed as distinct from those in other areas of medicine (Emanuel, von Gunten and Ferris, 1999).

Finally, the exclusion criterion based on medical setting applied in this review has been applied in other literature reviews, conceptual reviews and meta-analyses of doctor-patient communication (for example, Zela et al, 2001 and Roter et al, 2002). More specifically, similar exclusion criteria have been applied

to reviews of the accompanied patient interaction literature. For example, Wolff and Roter (2012) excluded studies that took place in emergency medicine, end of life care, therapeutic, and psychiatric settings from their meta-analysis of family presence in routine (adult patient) medical visits.

2.2 Data extraction and analysis

Given the aims and objectives of this literature review, a four-stage data extraction and analysis procedure was adapted. A flow chart detailing this procedure can be found in the Appendix (see Appendix, figure 5).

In the first stage of analysis all studies identified for inclusion were examined and the broad methodological perspective used and the age range of the patient sample(s) were described.

In the second stage of the analysis the proportion of patients accompanied to visits and the demographic and clinical characteristics of accompanied patients and their companions was assessed.

In the third phase of analysis, all observational studies included in the review were selected, and the methodological approaches of these studies (the methods used to analyse data) were examined in more depth. Studies solely using survey, questionnaire and interview based methods were excluded from this phase of the analysis. Only empirical studies using observational methods and/or analysis of audio or video recordings of accompanied patient interactions were analysed.

In the fourth phase of analysis, the effects of the presence of companions described in observational studies of (audio or video recorded) adult patient-doctor interactions were analysed. This necessitated the exclusion of all studies exploring child patient groups and studies solely using survey, questionnaire, interview based and (non-)participant observation methods.

Studies of accompanied adult interactions that had taken place in Alzheimer's, dementia and memory clinics were also excluded from this fourth phase of the analysis. Interactions with patients with Alzheimer's disease, dementia or memory problems were considered different (distinct) from interactions with

(adult) patients in other clinical settings. For example, patients with dementia are accompanied much more regularly to primary care visits (60% of visits; Fortinsky, 2001) compared to other adult patient groups (16% of visits; Schilling et al, 2002). Patients with dementia and Alzheimer's disease have also been shown to occupy comparatively little (between 10% to 16%) of the discourse space available in accompanied medical encounters (Sakai et al, 2011 and Schmidt et al, 2009). Similarly, people with memory problems have been observed as marginalised from discussions in accompanied medical interactions (Karnieli-Miller et al, 2009).

The 'effects of companions' was analysed thematically, resulting in five topical areas of discussion: 1) duration and participant discourse spaces, 2) formation of coalitions, 3) role of the companion, 4) topical areas of discussion, and 5) participant behaviours and patient outcomes.

3. Results

Summaries of the studies identified for inclusion in the review are presented in the Appendix. As space was limited, to aid readability these review summaries are presented across two tables.

The first of these figures (Appendix, table 2) details the author(s) and the year the study was published, the age group of the study (patient) sample, the number of participants (described in terms of the primary study (predominantly patient) sample, or in the case of literature reviews/meta-analyses the number of studies identified for inclusion), the medical setting in which the study was conducted, the country of origin, the main method(s) used to analyse data, the main method(s) used to collect data, and in which phases of the analysis (as described in the Methods section) the study was used in.

The second figure (Appendix, table 3) details the author(s) and the year the study was published, a description of the study (more information about the study sample, data collection methods and analytical methods are presented here), the focus of the analysis, a summary of the study's findings (or a description of the conceptual framework) and in which phases of the analysis (as described in the Methods section) the study was used in.

3.1 Study characteristics

51 studies that explored accompanied medical interactions were identified for inclusion in the review. The studies were grouped into four categories according to patient sample age-range: children, adults of 'all ages', older adults, and patients of 'all ages'.

Of the studies identified for inclusion, 14 explored child (and/or adolescent) patient samples (under 18 years of age), 22 studies examined older adult (including elderly) patient samples (over 60-65 years of age), 12 studies assessed adult patient samples of 'all ages' (over 18 years of age) and three studies investigated patient samples of 'all ages' (children and adults).

The studies were classified according to the broad methodology used (literature review, meta-analysis, conceptual framework, quantitative, qualitative, or mixed methods).

Two literature reviews of accompanied paediatric encounters (Tates and Meeuwesen, 2001 and Cahill and Papageorgiou, 2007a) and a paper presenting a theoretical framework for understanding patient partnership in paediatric clinics (Gabe et al, 2004) were identified for inclusion. In addition, three studies that used quantitative methods (Bindera et al, 2010; Pantell et al, 1982 and Wassmer et al, 2004), three studies that used qualitative methods (Buchbinder, 2009; Stivers, 2001 and Cahill and Papageorgiou, 2007b), and five studies that used mixed methods to explore accompanied paediatric encounters (van Staa, 2011; Aronsson and Rundstrom, 1988; Tates and Meeuwesen, 2000; Tates et al, 2002a and Tates et al, 2002b) were identified.

22 of the studies explored accompanied medical interactions with older patients (over 60-65 years of age). Of these, one literature review (Beisecker, 1996) and two papers that presented conceptual frameworks (Fortinsky, 2001 and Adelman, Greene and Charon, 1987) were identified. Of the remainder, four studies used qualitative methods (Karnieli-Miller et al, 2009; Ellingson, 2002; Hasselkus, 1992 and Coe and Prendergast, 1985), 13 studies used quantitative methods (Wolff and Roter, 2012; Sakai et al, 2011; Zaleta et al, 2010; Oguchi et al, 2010; Schmidt et al, 2009; Clayman et al, 2005; Ishikawa et al, 2005a; Ishikawa et al, 2005b; Prohaska and Glasser, 1996; Glasser and Prohaska,

1999; Glasser, Prohaska and Gravdal, 2001; Shields et al, 2005 and Beisecker, 1989) and two used mixed methods (Greene et al, 1994 and Tsai, 2000) to analyse data.

Twelve studies that investigated accompanied encounters with adult patients of 'all ages' (over 18 years of age) were identified for inclusion in the review. These included one meta-analysis (Wolff and Roter, 2011) and one theoretical framework (Street and Millay, 2001). Of the remaining studies, seven used quantitative methods (Rosland et al, 2011; Eggly et al, 2011; Eggly et al, 2006; Schilling et al, 2002; Beisecker et al, 1997; Labrecque et al, 1991 and Street and Gordon, 2008), two used qualitative methods (Beisecker and Moore, 1994 and Gilliam et al, 2009) and one used mixed-methods (Cordella, 2011) to analyse data.

Three studies were identified that examined accompanied interactions with patients of 'all ages' (children and adults). Of these, one study used quantitative methods (Brown et al, 1998) and one used mixed methods (Main et al, 2001). Finally, one study was identified for inclusion that compared the perspectives of paediatricians and geriatricians using mixed methods (Barone, Yoels and Clair, 1999).

3.2 The proportion of patients accompanied to medical visits and accompanied patient and companion characteristics.

Authors have reported that approximately one-third of all patients (regardless of age) are accompanied to medical visits (Brown et al, 1998 and Main et al, 2001). However, it appears that children and older (especially elderly) patients are significantly more likely to be accompanied. In a prospective observational study, Brown et al (1998) recruited eight family doctors to complete 100 consecutive surveys, resulting in 783 cases available for analysis. Doctors reported that nearly one third (30%) of their patients were accompanied to visits. Children and elderly patients (over 75 years of age) were significantly more likely to be accompanied. Similarly, Main et al (2001) analysed outpatient encounters with 1600 patients and found 560 patients (35%) were accompanied to their visit, the majority of which were children and older (elderly) patients.

As one might expect, findings suggest that children are more frequently accompanied to medical appointments. A survey of 18 paediatric and 18 geriatric doctors found that paediatricians estimated 96% of their patients were regularly accompanied to visits, whereas geriatricians estimated 55% of their patients were regularly accompanied to visits (Barone, Yoels and Clair, 1999).

Although initially very high, the proportion of children accompanied to visits appears to decrease with age. For example, Staa (2011) reported that only 70% of 39 adolescent patients in his outpatient sample were accompanied. Similarly, Bindera and colleagues (2010) observed that 64% of the 674 adolescent patients in their general practice sample were accompanied.

Authors have observed that older patients are frequently accompanied when they attend medical visits (Beisecker, 1996). Excluding those studies that examined Alzheimer's disease and dementia patient groups, the research included in this review suggests that 33% to 57% of older and elderly patients are accompanied to medical visits (Wolff and Roter, 2012; Ishikawa et al, 2005; Schilling et al, 2002; Glasser, Prohaska and Gravdal, 2001; Glasser and Prohaska, 1999; Brown et al, 1998; Prohaska and Glasser, 1996 and Clayman et al, 2005).

However, the proportion of older adult patients accompanied to visits appears to vary according to the medical setting in which the visit takes place. For example, authors have shown that approximately 20% of older people are accompanied to primary care visits (Wolff and Roter, 2012 and Adelman, Greene and Charon, 1987). However, the proportion of older adults that are accompanied to visits appears to increase if the older person requires 'disease specific' care or if the study takes place in a specialist (or outpatient) setting. For example, Fortinsky (2001) reported up to 60% of dementia patients are accompanied to primary care appointments. In addition, Barone, Yoels and Claire (1999) reported that geriatricians in their study estimated 55% of their older patients were accompanied to hospital or specialist centre medical appointments.

The literature also suggests that the proportion of older adult patients accompanied to visits varies according to a number of other patient characteristics. For example, older (elderly) patients (over 75 years of age) have been shown significantly more likely to be accompanied to medical visits than their younger (60 to 75 years of age) counterparts (Beisecker, 1989; Brown et al, 1998 and Ishikawa et al, 2005a and 2005b). In addition, researchers have observed that those with poorer functional or health status (Greene et al, 1994; Glasser and Prohaska, 1999; Glasser, Prohaska Gravdal, 2001, and Ishikawa et al, 2005a and 2005b), that are less educated (Prohaska and Glasser, 1996 and Ishikawa et al, 2005a and 2005b) and those on lower incomes (Prohaska and Glasser, 1996; Glasser and Prohaska, 1999 and Glasser, Prohaska Gravdal, 2001) are significantly more likely to be accompanied.

The proportion of adult patients (over 18 years of age) that are accompanied to medical visits was difficult to determine. Wolff and Roter (2011) reported that the number of adult patients that were accompanied to visits in their meta-analysis was 46%. However, of the 13 studies included in the meta-analysis, the majority included older adult patient (over 60-65 years of age) samples, with a number of the studies conducted in specialist settings (for example, oncology).

Older adult patients have been reported as significantly more likely to be accompanied to medical appointments compared to younger adult patients. Beisecker (1989, 1996) reported that older patients over 60 years of age were significantly more likely to be accompanied to medical appointments than younger adults aged 25 to 59 years. Likewise, Schilling et al (2002) compared 115 accompanied and 121 unaccompanied patients and found that older patients (over 44 years of age) were significantly more likely to be accompanied in the examination room compared to younger adult patients (under 44 years of age). Therefore, the actual rate of 'all age' adult patient accompaniment to 'routine' visits is anticipated to be much lower than that reported by Wolff and Roter (2011). For example, in their study of 1294 primary care visits, Schilling et al (2002) observed that just 16% of adult patients (over 18 years of age) were accompanied to their visit.

Research has suggested that adults with chronic conditions (for example, diabetes) are more likely to be accompanied to primary care visits than those without chronic conditions. For example, Gilliam et al (2009) reported that 32% of epilepsy patients in their sample were accompanied during community (home-based) visits. In addition, Rosland et al (2011) found that 48% of (adult) patients with diabetes or heart failure reported regular accompaniment to primary care visits, and that patients with four or more comorbid illnesses were more likely to be accompanied. Likewise, Schilling et al (2002) found that patients with cases of greater medical and social complexity (as perceived by the doctor) were significantly more likely to be accompanied.

Similarly, a greater proportion of patients with serious, life threatening illnesses are accompanied to medical visits. As Cordella (2011) and Beisecker (1997) have observed, accompanied encounters are quite frequent in cancer care. Beisecker and Moore (1994) reported that oncologists estimated that three-quarters of their cancer patients were accompanied to appointments, with other studies putting this figure at around two-thirds (Oguchi et al, 2010). These patients are equally likely to be accompanied to their appointment regardless of their age. Labrecque et al (1991) found that age was not a determining factor in an oncology setting; younger patients (18-59 years of age) were as likely to be accompanied to visits as older patients (over 60 years of age).

Findings from the literature suggest that, regardless of patient group or setting, the majority of accompanying persons are female; studies have shown that 69% to 93% of accompanying persons are women (Wolff and Roter, 2011; Barone, Yoels and Clair, 1999; Street and Gordon, 2008; Brown et al, 1998; Greene et al, 1994 and Main et al, 2001). Similarly, in paediatric medical encounters it has been observed that the mother usually accompanies the child (Barone, Yoels and Clair, 1999; Brown et al, 1998; Main et al, 2001; Stivers, 2001 and Tates and Meeuwesen, 2000).

In the studies identified for inclusion in this review, older (and elderly) adult patients were most often accompanied by their spouse or partner (range 30% to 55%), their adult child (mainly daughters) (range 18% to 72%), or to a lesser extent, another family member, friend, or neighbour (range 6% to 45%) (Clayman et al, 2005; Ishikawa et al, 2005a; Barone, Yoels and Clair, 1999; Prohaska and Glasser, 1996; Hasselkus, 1992; Glasser, Prohaska and Gravdal,

2001 and Tsai, 2000). The rate of spousal accompaniment was higher (range 50% to 63%) and the rate of adult child accompaniment comparatively lower (range 22% to 35%) in Alzheimer disease, dementia and memory problem patient groups (Zaleta et al, 2010; Schmidt et al, 2009 and Sakai et al, 2011).

Scant data exist about the characteristics of 'all age' (younger) adult patient companions. However, authors have reported that the companions of 'all age' adult patients are predominantly family members, and most often the patient's spouse or partner (Schilling et al, 2002; Main et al, 2001; Brown et al, 1998 and Gilliam et al, 2009). For example, Main et al (2001) analysed 1600 adult patient encounters and found that 96% of accompanied patients were accompanied by a family member. Of these, 48% were accompanied by a spouse (29% were accompanied by their wife, 19% by their husband) and 19% were accompanied by their adult daughter.

The identity of companions that accompany adult cancer patients appears more mixed. Nevertheless, the primary companion appears to be the patient's spouse or partner. Labrecque et al (1991) observed that of the cancer patients accompanied to visits in their study (n=99), 64% were accompanied by a spouse, 10% by an adult child, 6% by another relative and 19% by unknown companions. In addition, Beisecker et al (1997) observed that 50% of the cancer patients in their study reported that their spouse was their primary companion, with the remaining primary companions consisting of parents (17%), other relatives (11%), children (11%) and friends (11%).

3.3 Methods used in observational studies of accompanied patient interactions

Of the 51 studies identified for inclusion in the review, 31 used non-participant observation methods and/or audio or video recorded data of accompanied patient interactions. 16 of these observational studies used quantitative methods, nine used qualitative methods, and six used mixed-methods to analyse data. The methodological characteristics of these studies are discussed below. Following this, a more in-depth discussion of the specific methods used to analyse observational data is offered.

Of the 16 observational studies identified that used quantitative methods, 11 used process analysis methods as the main means of analysis. Two of these

studies used modified versions of the Bales IPA system (1950) of analysis (Pantell et al, 1982 and Beisecker, 1989). Six of the studies used the Roter Interaction Analysis System (RIAS) (Roter, 1977) or amended RIAS methods to analyse data (Wolff and Roter, 2012; Zaleta and Carpenter, 2010; Ishikawa et al, 2005a and 2005b; Clayman et al, 2005 and Wassmer et al, 2004). The remainder used other process analysis methods (outside of conventional RIAS and the Bales IPA systems) to analyse data (Labrecque et al, 1991; Street and Gordon, 2008 and Schmidt et al, 2009). Finally, five studies used content analysis (coding) as the principal method of analysis (Eggly et al, 2011, and 2006; Sakai et al, 2011; Oguchi et al, 2010 and Shields et al, 2005).

Six observational studies were identified that used mixed methods to analyse data. Of these, four used microanalytic and content analysis methods (Cordella, 2001; Tates and Meeuwesen, 2000; Tsai, 2000 and Aronsson and Rundstrom, 1988). In addition, a study by Greene et al (1994) was identified that used a distinctive mixed method framework – the Multidimensional Interaction Analysis (MDIA) system. Lastly, van Staa (2011) used a range of quantitative and qualitative methods to analyse data.

Nine observational studies were identified that used qualitative methods to analyse data. Of these, three used Conversation Analysis (CA) (Buchbinder, 2009; Cahill and Papageorgiou, 2007b and Stivers, 2001) and the remaining six studies used other or combined microanalytic methods (Gilliam et al, 2009; Karnieli-Miller et al, 2009; Ellingson, 2002; and Main et al, 2001; Hasselkus, 1992 and Coe and Prendergast, 1985).

3.3.1 Quantitative methods

The most popular quantitative method used in observational studies included in this review was process analysis.

Process analysis was derived from Bales (1950) Interactive Process Analysis (IPA) system, made popular by Korsch and colleagues (for example, Korsch, Gozzi and Francis, 1968) as a means for studying medical interactions. Researchers that use process analysis quantify (code) participant behaviours using taxonomies of behaviours (such as information giving, requests, questions, displays of approval, negativity, etc.) and compare these to outcome

measures (for example, patient satisfaction). Researchers that use process analysis methods ordinarily analyse audio and video recorded consultations directly, without the use of a transcript.

Pantell et al (1982) and Beisecker (1989) used modified versions of the Bales (1950) IPA system to analyse triadic paediatric medical encounters. This is not unusual; many analysts modify process analysis systems in accordance with their research aims and objectives. For example, Pantell et al (1982) expanded on the Bales IPA system, and modified the coding frame to identify who was saying what, to whom and during which phase of the consultation they were saying it (for example, during the symptom presentation phase). These findings were then measured against participant demographic and situational (encounter) characteristics.

However, by far the most popular approach of the different process analysis methods identified was the Roter Interaction Analysis System (RIAS). Developed by Roter (1977), the RIAS is a modification of the (Bales, 1950) IPA system, adapted for use in medical communication (Charon, Greene and Adelman, 1994). The RIAS allows for the coding and quantification of communication categories and includes analysis of 'global affect ratings' to determine the overall character of the consultation, communication patterns and styles. In addition, the RIAS allows for the coding of content-specific categories. Participant communication behaviours, 'global affect ratings' and topical content are measured against participant characteristics and/or outcome measures (Roter and Larson, 2002).

Similar to the Bales IPA system (1950), the RIAS system (1977) has been adapted and modified by researchers to suit research aims and objectives. Consequently, studies using RIAS methods to analyse accompanied interactions use a variety of different (observational and outcome) measures. Certainly most (if not all) of the observational studies included in this review that used RIAS methods employed a diverse range of modified or expanded variables and outcome measures.

As a case in point, Ishikawa et al (2005a) used a modified version of the RIAS to explore dyadic and triadic medical encounters with elderly patients. Additional RIAS coding categories were developed during the course of the study and grouped into 'supportive comments' and 'non supportive comments'. In addition, the mean number and mean percentage of total utterances for each participant in dyadic (unaccompanied) and triadic (accompanied) consultations were coded and categorised as occurrences of question asking (biomedical, psychosocial, other), information giving (biomedical, psychosocial, other), emotional responsiveness/expression, partnership-building, positive talk, negative talk, orientation, social talk, other supportive comments for patient/companion, non-supportive comments for patient/companion, other patient-companion talk, and doctor-companion talk about the companion.

In comparison, Wassmer et al (2004) combined RIAS categories, such as positive talk and partnership building, to form a category labelled affective behaviour. Directive talk was also added as a new coding category. In the study, the doctor's interactions were classified as affective talk (expressing concerns and worries), social conversation (small talk), and instrumental talk (asking questions, giving information, seeking information and directive talk). Child and parent behaviours were categorised as affective talk, social conversation, giving information, and seeking information.

Clayman et al (2005) also used a modified version of the RIAS system. In their study, patient and accompanying person decision-making behaviours were analysed based on an expanded framework of autonomy enhancing behaviours (facilitating patient understanding, patient involvement, and doctor understanding) and detracting behaviours (controlling the patient and building alliances with the doctor). The authors also included eight elements of informed medical decision making; discussion of the clinical issue, discussion of the alternatives, discussion of the benefits of the alternatives, discussion of the risks of the alternatives, discussion of uncertainties associated with the decision, assessment of patient understanding, assessment of patient preference, and patient request for a particular remedy or test.

Similarly, studies identified here that used process analysis methods to analyse data employed a variety of different outcome (process) measures. For example, Ishikawa et al (2005a) explored patients' expectations of companion's roles in

encounters, and companions' intention of their own role, Wolff and Roter (2012), Zaleta et al (2010) and Ishikawa et al (2005b) examined patient-centred communication, Clayman et al (2005) investigated patient decision-making, and Wassmer et al (2004) studied parent and child assessments of doctors' communication skills.

Other studies identified for inclusion in the review (Schmidt et al, 2009; Street and Gordon, 2008; Bindera et al, 2010 and Labrecque et al, 1991) also used process analysis methods. However, these studies did not use 'conventional' Bales IPA system or RIAS derived methods.

Street and Gordon (2008) coded and categorised participant utterances according to communication categories (for example, patient and companion participation and doctors' use of facilitative communication) and compared the number of participant utterances to coded behaviours. Finally, patient satisfaction scores were compared to companion roles and the verbal activities of companions (the verbal contributions to patient-party talk).

Labrecque et al (1991) modified the Physician Behavior Check List (PBCL) for use in an outpatient setting. Coded physician behaviours included addressing the patient, inquiring about overall state, discussing signs and symptoms, discussing test results, describing future tests or treatments, and providing verbal support. Time spent during visit, reason for the visit, and performance status (using the Eastern Cooperative Oncology Group scale, ECOG) were also recorded. Variables were then measured against the results of Patient Satisfaction Questionnaires (PSQ).

Finally, Schmidt et al (2009) quantified participant discourse spaces and analysed patient participation against patients' cognitive status.

Five observational studies included in the review used content analysis methods to examine data. As described in chapter three, content analysis involves the rigorous examination of words or themes to assess the presence, meaning and relationships between concepts in order to extract quantifiable measurements (Krippendorff, 1980).

Of the five observational studies identified that used (quantitative) content analysis methods, three used specific (standardised) measuring tools to code data. Oguchi et al (2010) coded data using the Verona Coding Definitions of Emotional Sequences for Cues and Concerns (Verona-CoDES-CC and VERONA-CoDES-P) and explored patients emotional cues/concerns and practitioner responses. Shields et al (2005) coded dyadic and triadic encounters using the Measure of Patient-Centered Communication (MPCC) and Rochester Participatory Decision-Making (RPAD) scales. Finally, to assess variations in question asking behaviours, Eggly et al (2011) coded interactions using the using the Karmanos Information Seeking Analysis System (K-ISAS).

The remaining two observational studies that used content analysis methods focused on different variables of interest. Eggly et al (2006) coded and analysed the frequency and topical content of discussions of 'bad news' in their data, and Sakai et al (2011) quantified participant discourse spaces and coded linguistic expressions of power.

3.3.2 Mixed methods

Of the six observational studies identified that used mixed methods to analyse data, four used microanalytic and content analysis methods (Cordella, 2001; Tates and Meeuwesen, 2000; Tsai, 2000 and Aronsson and Rundstrom, 1988). These studies used a combined approach to data analysis; they employed microanalytic methods to determine quantitative units of analysis and interpreted quantitative results with reference to microanalytical observations. Three of these studies were unusual in that they sought to quantify interaction sequences (Tates and Meeuwesen, 2000; Tsai, 2000 and Aronsson and Rundstrom, 1988).

Cordella (2001) identified the linguistic functions associated with the roles of companions in accompanied medical encounters. Detailed microanalytic analysis of the structure and sequence of interactions using CA derived methods resulted in a typology of accompanying person roles that were coded and quantified. However, whereas Cordella (2001) sought to quantify the frequency of accompanying person roles, Aronsson and Rundstrom (1988) and Tates and Meeuwesen (2000) went considerably further in merging

methodological perspectives in their analyses - they quantified the sequential order of participant interactions.

Aronsson and Rundstrom (1988) used the Turn Allocation System (TAS) and microanalytic methods to analyse paediatric medical encounters. The authors categorised doctor initiations as child specific allocated turns (CATs) and adult specific allocated turns (AATs). A particular focus was placed on CATs, with adult responses including: answering for the child, and providing correction, elaboration or validation of child responses.

Tates and Meeuwesen (2000) used an expanded version of the Turn Allocation System (TAS) to examine the asymmetry and strategic control of doctor–parent–child communication. The authors also analysed how these features had changed over time (over 20 years) and how the child’s age effected turn taking in the encounters. The authors examined interactive control and dominance by analysing ‘quantitative control’ (conversational contribution) and ‘strategic control’ (strategic interruptions). Based on the work of Aronsson and Rundstrom (1988), the intended allocation of participant turns were identified and measured against intended participant responses and actual participant responses. Participant turns were analysed according to initiation, initiatives combined with allocation (who is talking to whom) and sequential patterns (responses to different types of turn allocation). However, whereas Aronsson and Rundstrom (1988) were mainly interested in child allocated turns (CATs), Tates and Meeuwesen (2000) modified the TAS system to include all participant interactions; they analysed patient allocated turns (PATs), doctor allocated turns (DATs), adult (doctor and parent) allocated turns (AATs), and ‘both’ allocated turns (BATs) (a participant addressed the two other participants simultaneously).

Using similar methods, Tsai (2000) explored the discourse sequences of participants in accompanied older adult patient interactions. In the analysis, Tsai (2000) differentiated between patient and companion information-providing cycles and non-information-providing cycles. Information-providing cycles were defined as sequences that included biomedical information, management information, pedigree information, daily routines, social activities and personality, and physical examination information. All other sequences were

defined as non-information-providing cycles. The extent that information-providing cycles were elicited or volunteered was examined.

The author identified six linguistic and interactional initiation mechanisms that prompted companions to participate. The first four of these mechanisms built on Rosenfeld's (1996) framework and involved identification and analysis of vocatives (the name of the addressee), third person deictic (for example, pronouns such as *'I'*, *'he'* or *'she'*), second (singular) person deictic (for example, second person pronouns such as *'you'*), and sequential discourse structures (the sequence of talk taking 'turns'). Tsai's (2000) resulting taxonomy included: personal deictic, relationship deictic, patient absence, and patient trouble as initiation cues. The remaining two initiation mechanisms analysed by Tsai (2000) were eye contact and code-switching (changing the language from Southern Min into Mandarin or vice-versa). Finally, the author identified and analysed eight discourse patterns of question-response sequences, where the patient-party (patient and accompanying person) provided information to the doctor.

One observational study was identified that used a distinct mixed method framework to analyse observational data - the Multidimensional Interaction Analysis (MDIA) system (Greene et al, 1994).

The MDIA system combines process and microanalytic methods to identify and analyse participant behaviours and the direction of communication in accompanied encounters. The focus of the MDIA system is the quality of questioning, informing, and supportiveness on specific topic areas by all participants (the doctor, patient and companion) (Adelman, Greene and Charon, 1987). Assessed on a set of global dimensions, the method aims to capture the overall affect and tone of the encounter and to characterise the third party's manner and style. For example, the companion's relationship with the doctor and/or patient is assessed; resulting in the companion being classified as 'friendly versus hostile', 'engaged versus diffident', 'patient versus impatient', 'egalitarian versus condescending' or 'respectful versus disrespectful'. The MDIA system also includes the analysis of other interactional behaviours, for example, interruptions, use of social amenities, compliments, negative remarks, misattributions of symptoms, allowances for functional deficits, joint decision-making, and third person pronouns (Adelman, Greene and Charon, 1987). The

authors report that other sentinel events (for example, patient attribution of illness, patient crying and periods of silence) can be included in the analysis and amended as necessary depending on the population and/or disease under study (Charon, Greene and Adelman, 1994).

In their 1994 study, Greene and colleagues presented five topical areas of analysis in their MDIA system: medical, personal habits, psychosocial, doctor-patient relationship, and other topics. The frequency of topics raised by participants (doctors, patients, companions and 'patient parties') were coded and calculated. In addition, the quality of patient and doctor questioning, informing and supportiveness (responsiveness) was assessed by coding responsiveness dimensions on a scale of one to four, with four representing high quality content. In the accompanied interactions, patient and doctor responsiveness to raised topics was also analysed. These features included: doctor responsiveness to patient raised topics, doctor response to doctor-raised topics, patient responsiveness to doctor-raised topics, and patient responsiveness to patient raised topics. Finally, a global assessment of doctor and patient behaviours were included in the analysis. Doctor behaviours included egalitarianism, patience, engagement, and respect. Patient behaviours included assertiveness, relaxation, friendliness, and expressiveness.

Finally, a study by Van Staa (2011) was identified that used a range of methodologies to analyse accompanied patient interactions. Alongside conducting face-to-face interviews, focus groups and web-based questionnaires, the author examined 30 outpatient visits with accompanied and unaccompanied adolescent patients, and employed Goffman's (1959) dramaturgical metaphor to analyse participant roles, behaviours and participation in the encounters.

3.3.3 Qualitative methods

Nine observational studies were identified in which qualitative methods were used to analyse data. In most of these studies, transcripts of video or audio-recorded encounters were subjected to close linguistic study and contextualization. Of the nine observational studies identified, all but two (Hasselkus et al, 1992 and Main et al, 2001) used transcripts (alongside recordings) of accompanied encounters in their analyses. Hasselkus et al

(1992) and Main et al (2001) used non-participant observation methods and did not record encounters.

Three of the observational studies included in the review used formal Conversation Analysis (CA) methods to analyse data (Buchbinder, 2009; Cahill and Papageorgiou, 2007b and Stivers, 2001). CA has been defined as the systematic analysis of the sequence and organisation (verbal and non-verbal) of 'naturally occurring' interactions (Drew and Heritage, 2006). Of the studies that used formal CA methods, each focused on a different aspect of accompanied encounters.

In a series of accompanied encounters with the same patient, Buchbinder (2009) explored the extent to which the (adolescent) patient's autonomy was facilitated and constrained by a companion (mother) and health professional. The author divided the encounters into three topical areas: problem identification, the development of solutions and moments of transition. Stivers (2001) explored a single medical encounter activity, 'establishing the reason for the visit' in her large dataset (of 100 paediatric encounters). Finally, Cahill and Papageorgiou (2007b) used CA to analyse participation in accompanied paediatric encounters, and analysed four aspects of interactions: seating positions, interruptions, inviting the patient to speak, and switching pause.

Six observational studies that used other or mixed microanalytic methods to analyse data were identified. In contrast to formal CA methods, discourse analysis and sociolinguistic methods do not necessarily focus on the form and sequence of interactions. Discourse Analysis (DA) and sociolinguistic methods also necessitate consideration of the social and cultural contexts of interactions alongside analysis of participant language and linguistic behaviour (Fishman, 1970).

Of the observational studies identified that used other or mixed microanalytical methods, two incorporated CA derived methods. Karnieli-Miller et al (2009) mapped the nature, form and manner of participant involvement in accompanied interactions. Similarly, Coe and Prendergast (1985) analysed the form, content and sequence of participant utterances - focusing on the formation of goal-orientated coalitions; the goals suggested, by whom they were suggested, to whom they were suggested, and how parties interacted to

achieve acceptance or (actively or passively) resist goals in the encounters.

A further three observational studies were identified which used sociolinguistic methods to analyse accompanied interactions; Gilliam et al (2009) focused specifically on (negative) side effect discussions in their study, Ellingson (2002) analysed companion roles, and Main et al (2001) explored family context discussions.

Finally, one observational study was identified that used DA methods. Hasselkus (1992) used a typology of 26 caregiving divided into two broad topical themes for discussion, 'healthcare' and 'life world' to analyse data. In the study, topical themes and problem situations were explored with reference to exchanges of meaning between patients, accompanying persons and doctors.

3.4 The effects of companions in observational studies of (recorded) accompanied adult patient interactions.

Of the 31 observational studies included in the review, 29 analysed audio or video recordings of encounters; two studies that used non-participant observation methods (Main et al, 2001 and Hasselkus, 1992) were excluded from further analysis. Of the 29 observational studies remaining, 21 explored accompanied medical interactions with adult patients.

Of the 21 observational studies that explored accompanied medical interactions with adult patients, 14 investigated interactions with older patients (over 60-65 years of age). Four studies that explored accompanied older patient interactions in Alzheimer's, memory and dementia clinic settings were excluded from further analysis (Zaleta and Carpenter, 2010; Schmidt et al, 2009; Sakai et al, 2011 and Karnieli-Miller et al, 2009). Ten studies of older patient accompanied interactions remained for analysis.

Of these ten observational studies, six used quantitative methods; five used process analysis (Beisecker, 1989) or RIAS methods (Wolff and Roter, 2012; Ishikawa et al, 2005a and 2005b and Clayman et al, 2005) and one used content analysis methods (Shields et al, 2005). The remaining four observational studies that explored accompanied older adult patient encounters

used mixed methods (Tsai, 2000 and Greene et al, 1994) or qualitative (microanalytic) methods (Ellingson, 2002 and Coe and Prendergast, 1985).

Seven observational studies were identified that explored accompanied interactions with adult patients of 'all ages' (over 18 years of age). Of these studies, five used quantitative methods; two studies used process analysis methods (Labrecque et al, 1991 and Street and Gordon, 2008) and three studies used content analysis methods (Eggy et al, 2011; Oguchi et al, 2010 and Eggy et al, 2006) to analyse data. The remaining two studies used mixed (Cordella, 2001) or qualitative (microanalytical) methods (Gilliam et al, 2009).

The 'effects of companions' was analysed thematically, resulting in five topical areas of discussion: 1) duration and participant discourse spaces, 2) formation of coalitions, 3) role of the companion, 4) topical areas of discussion, and 5) participant behaviours and patient outcomes. These are presented below.

3.4.1 Duration and participant discourse spaces

Since Beisecker (1989) reported no significant difference in the length of dyadic (patient and doctor) and triadic (patient, companion and doctor) consultations with older patients – and suggested that accompanying persons take time away from the patient - there has been a growing interest in the duration and (discourse space) structures of accompanied medical interactions.

Six observational studies were identified that explored differences between the duration of unaccompanied and accompanied adult patient interactions, using either time (minutes) or word/utterance counts (as proxy measures) to measure consultation length. However, the findings of these studies are mixed.

Accompanied visits were found to be marginally longer than unaccompanied visits in all of these studies. However, some studies reported that accompanied interactions were significantly longer ($p < 0.05$) than unaccompanied visits (Ishikawa et al, 2005a and Labrecque et al, 1991) and others studies reported no significant difference in duration (Wolff and Roter, 2012; Beisecker, 1989 and Greene et al, 1994). In addition, studies that used total word count and number of utterances as proxy measures of duration (Shields et al, 2005 and Street and Gordon, 2008) also reported no significant difference. Finally,

Ishikawa et al (2005a) reported two different types of triadic consultations in their data, a 'typical' triad of patient, doctor and companion (who was not a patient) (n=37) and a 'double-patient' triad consisting of a doctor and two patients (who were both 'seen' in the consultation) (n=26). The authors observed that the 'double-patient' consultations were significantly shorter than unaccompanied patient consultations ($p < 0.05$).

Only four observational studies examined the discourse space of participants in unaccompanied and accompanied adult patient interactions (Wolff and Roter, 2012; Ishikawa et al, 2005a; Street and Gordon, 2008 and Shields et al, 2005). Discourse space is the proportional measure of participant talk (contributions) in a consultation. Authors used a variety of units of analysis to measure discourse space, including words (Shields et al, 2005), utterances (Street and Gordon, 2008 and Ishikawa et al, 2005a), statements (Wolff and Roter, 2012) and turns (Shields et al, 2005).

Of the studies that explored participant discourse space, none reported a significant difference in the discourse spaces of patients in dyadic (unaccompanied) interactions and patients and companions combined ('patient parties') in accompanied interactions (Street and Gordon, 2008; Ishikawa et al, 2005; Wolff and Roter, 2012 and Shields et al, 2005). Wolff and Roter (2012) observed that the discourse space of patients in unaccompanied interactions was 47% and the combined contribution of patients and companions in accompanied interactions was 48%. Similarly, Ishikawa et al (2005a) observed the discourse space of patients in unaccompanied interactions was 46% and the combined discourse space of patients and companions in accompanied interactions was 51%. Shields et al (2005) reported that patients contributed 48% of the conversation in unaccompanied encounters, and the patient and companion contributed 48% in accompanied interactions. Albeit proportionally lower, Street and Gordon (2008) also found no significant difference between these discourse spaces; they reported the average number of patient utterances in unaccompanied interactions to be 41% and the average number of patient and companion utterances in accompanied interactions to be 40%.

Correspondingly, the difference between the discourse space of doctors in unaccompanied and accompanied encounters was not found to be significant in any of the studies (Street and Gordon, 2008; Ishikawa et al, 2005a; Wolff and

Roter, 2012 and Shields et al, 2005). However, Shields et al (2005) reported that doctors made significantly longer turns in encounters when an accompanying person was present in their data ($p < 0.02$).

Only two studies analysed differences between the discourse space of patients in unaccompanied and patients in accompanied interactions. Ishikawa et al (2005a) observed that patients contributed significantly less talk ($p < 0.05$) in triadic encounters (29.1%) compared to one-to-one consultations (45.9%). Shield's et al (2005) found that patients in their data spoke 270.3 fewer words in accompanied encounters, but that this difference was not significant.

Three of the studies explored differences in patient and companion discourse spaces in accompanied interactions. However, the results of these analyses are mixed, and the average discourse space of companions varies widely.

Ishikawa et al (2005a) reported that companions occupied 22% of the discourse space and patients occupied 29% of the discourse space in their accompanied interactions. The maximum companion participation was reported to be 54%, whereas in nearly a third (20) of the triadic encounters the companion made fewer than 15 utterances. In encounters where companions contributed at least 15 utterances, patients contributed more than companions in 27% of cases. In addition, the authors observed that 26 companions (41%) made more contributions than the patient they accompanied did. In contrast, Shields et al (2005) found that patients occupied an average of 40% of the discourse space in accompanied consultations, and companions occupied just 8%. The authors reported that accompanying persons spoke relatively little (an average of 313.6 words per consultation) and had shorter speeches and fewer speech turns compared to patients and doctors (Shields et al, 2005). Finally, Street and Gordon (2008) reported that patients in accompanied encounters made an average of 107 utterances (27%) in their data, significantly more than accompanying persons (54 utterances, 15%) ($p < 0.001$).

3.4.2 Formation of coalitions

Only one of the observational studies included in the analysis explored the formation of coalitions. Coe and Prendergast (1985) investigated seven patient-companion encounters using microanalytic methods. The authors observed that coalitions varied in duration (ranging from 10 to 65 lines of transcript), topic, and the objectives and the alignment of members. Common coalition objectives were found to include information seeking, obtaining permission, obtaining compliance and ending the encounter.

The authors found that several (multiple) coalitions formed within the bounds of a single (triadic) consultation. As one might expect, the strongest coalition identified in the interactions was the patient-doctor alliance. Coe and Prendergast (1985) observed that 'patient party' (patient and companion) coalitions tended to occur when doctors were preoccupied and did not centre their attention on the 'patient party'. When the doctor directed attention to the companion at the expense of the patient, a doctor-companion coalition occurred. When the doctor tried to readdress imbalances in power (by restoring power to the patient) a doctor-patient coalition occurred. The authors also reported that attempts to form coalitions did not always succeed in the data. The authors observed that some companions made efforts to form coalitions with doctors to achieve their aims and objectives, however, that these efforts were most often deflected by the doctor, who was typically observed to redirect the question to the patient or change topic.

The authors concluded that more coalitions occurred in interactions when information was not easily obtainable from patients and doctors were dependent on caregivers for information.

3.4.3 Role of the companion

As described in the Introduction, Simmel (Wolff, 1950) suggested three companion roles: '*mediator*', '*tertius gaudens*', and '*oppressor*'. Following on from this initial premise, participant roles have been examined in considerable detail in accompanied adult patient encounters - to such an extent that numerous companion role typologies have emerged. Many of the observational studies identified in this review that explored accompanied adult patient encounters included exploration of the roles of companions.

Using the typology proposed by Adelman, Greene and Charon (1987), Ishikawa et al (2005a) classified companions as occupying 'advocate', 'passive participant', or 'antagonist' roles. The authors also explored the intended, expected and actual roles of participants in accompanied encounters. Street and Gordon (2008) quantified companion verbal activities and classified companions as occupying 'advocate', 'partner' or 'passive' roles. Coe and Prendergast (1985) observed that accompanying persons occupied 'medication manager', 'interpreter', 'negotiator', or 'caretaker' roles in their data. Beisecker (1989) reported that companions in her data occupied 'watchdog', 'significant other', or 'surrogate patient' roles. Ellingson (2002) identified eight companion roles: 'memory aid', 'emotional support', 'transcriber', 'aid in decision making', 'companion', 'elaborator', 'advocate', and 'interpreter'. Finally, Cordella (2011) identified seven accompanying person roles: 'secretary', 'carer', 'financial assistant', 'health advisor', 'social communicator', 'reporter' and 'partner'. A common finding in all these studies was that companions occupied multiple roles during the bounds of a single encounter, however, that some roles were occupied more frequently than others were.

Given the variety of companion roles described, not all are discussed here. A more detailed description of the research by Cordella (2011) and Street and Gordon (2008) is offered, as these were the only two observational studies identified that explored companion roles in ('all age') adult patient encounters (as opposed to older adult patient encounters). Finally, the findings of Ishikawa et al (2005a) are discussed in more detail, as this was the only study identified that explored the intended, expected and actual roles of companions.

Cordella (2011) analysed companion roles in nine accompanied (triadic) follow-up encounters in an outpatient cancer clinic using content analysis and microanalytic (CA derived) methods. Seven accompanying person roles were identified.

Accompanying persons that occupied the role of 'secretary' were observed to undertake administrative duties on behalf of the patient - they assumed paperwork duties (for example, insurance claims), requested appointments, confirmed dates, and checked contact details. The role of 'carer' described accompanying persons that monitored the patient's health and well-being and were supportive of the patient. Functions of the role included, checking medical

results, medical procedures, medical information and medical knowledge, confirming the dosage of medicines, timing of medicines, patient diet, medical prescription and examination orders, asking for prescriptions, buying medicines for the patient and showing empathy for the patient.

The role of 'financial assistant' was quite narrow, and described accompanying persons that disclosed financial information about the patient, and the financial impact the patient's condition had on the family. The 'health advisor' role described companions that provided a lay-diagnosis, health information and health conceptualization, described changes in the patient's symptoms and behaviours, reminded the patient to raise health issues with the doctor, and showed health competence. The 'social communicator' role described companions that discussed social information about the patient that may not have been directly related to the clinical issue, but that may be significant information to the doctor (as proposed by Mishler, 1984), for example information about family issues, the patient's identity and social activities.

Companions who assumed the role of 'reporter' were defined as answering on behalf of the patient, including instances where the doctor directly addressed the patient and the accompanying person answered on their behalf. Based on their continued daily observations, 'reporters' were described as taking ownership of the patient's health. The final role identified was the 'patient-companion partnership' role. Companions that occupied this role engaged in joint discourse with the patient. In this role, conventional conversational rules were not violated, the companion did not intrude on the patient's talk and the conversation was a collaborative effort, even though the patient and companion may not have agreed.

Cordella (2011) observed that companions occupied multiple roles during the interactions. Of the seven accompanying person roles, 'carer' was used most frequently observed (a total of 52 times), and 'carer' and 'health advisor' (observed 31 times) companion roles were displayed across all interactions. Accompanying persons who occupied the role of 'health advisor' were usually observed to be the patient's main carer, or were responsible for closely looking after them. The 'partnership' role was also frequently displayed in the encounters (a total of 39 times), although it was not used in two of the consultations. However, the author observed that when the 'partnership' role did

emerge, it often resulted in significant contributions. 'Secretary' and 'financial assistant' roles occurred least frequently in the data (only featuring in two and three of the consultations respectively). Cordella (2011) concluded that accompanying persons can play a pivotal role in medical encounters, even when companion views are not consistent with those of the patient. The author observed that companions can relieve patients of many daunting tasks, were generally supportive, and provided additional, valuable information that may not have emerged in their absence.

Street and Gordon (2008) quantified the participation behaviours of companions by calculating companion contributions to patient party talk (the combined contributions of the patient and companion). Based on these scores, three companion roles were identified: 'advocates', 'partners' and 'observers'. The authors found that 49% of companions in their data played a 'passive' role (contributing <40% to patient party talk), 33% played an 'advocate' role (contributing >60% to patient party talk) and 18% were classified as 'partners' (contributing 40-60% to patient party talk). The authors observed that the role the companions played in the encounters ('advocate', 'partner' or 'passive') were not significantly associated with patient characteristics (age, education, race, physical and mental health status) or the doctor's use of facilitative communication.

Ishikawa et al (2005a) observed that the most frequent companion role observed in their dataset was that of patient 'advocate'; demonstrated when companions showed agreement with the patient, supported the patient's agenda, facilitated the patient's talk, and provided information and asked questions to the doctor. Relatively few companions were observed to occupy the role of 'passive' participant in the data, and only a small minority of companions were observed to occupy the role of 'antagonist' (criticised the patient, appealed to the doctor's authority in an attempt to influence the patient, or discussed their own health concerns).

Ishikawa et al (2005a) also explored patient expectations of direct and indirect companion roles and companion expectations of their (intended) roles during the visits. To examine patient expectations of companion roles, questionnaires were developed consisting of two three-point Likert scales. The first captured patient expectations of the indirect role of the accompanying person to: (1)

remember what the doctor had told them, (2) repeat or clarify the doctor's talk for them, and (3) facilitate patient talk. The second captured patient expectations of the direct role of the accompanying person to: (4) provide medical information, (5) provide information about lifestyle, and (6) ask questions to the doctor. Finally, six parallel items, divided into two sub scales, were developed to assess the companion's intention of their role during the visit. Questionnaires were administered pre-visit and responses were analysed against actual participant roles observed during encounters.

The authors found significant differences between patient and companion intentions of the companion's role during the visit. Companion intentions to assume a direct (communication) role (provide medical information, provide psychosocial information (lifestyle), and ask questions to the doctor) were significantly higher than patient expectations ($p < 0.001$). Of all six roles assessed, the indirect role of the accompanying person to 'remember what the doctor had told them' was rated the highest by patients and companions.

Disparate expectations and intentions were analysed against patient and companion characteristics. Patient expectations of the companion roles were not found to be significantly associated with companion characteristics. However, when the patient was older and in poorer health, the companion's indirect and direct role intentions were higher. Direct (communication) role intentions were lower among companions who were older than the patient, or the patient's spouse, compared to younger or adult child companions. The companion's direct (communication) role was higher for companions that were the patient's primary caregiver. Multiple regression of the direct role sub scale found that expectations of the companion's role were higher among male and poorer health status patients. Calculation of regression coefficients for physical and mental health subscales suggested that the direct role intentions of companions were higher when the patient they accompanied had poor physical and mental health scores. However, patient expectation of the companion's direct role was only higher if the patient scored lower on the mental health subscale.

The direct and indirect communication behaviours of companions were analysed. Companion participation was calculated as the proportion of companion talk in the consultation. When patient expectations of the companion (a direct and/or indirect role) were higher, or when companion expectations of their (direct and/or indirect) role were higher, the companion was more verbally active, gave more information (biomedical/psychosocial) and asked more questions. When patients had higher expectations of their companion occupying an indirect role, the companions were found to be more supportive of patient talk (Ishikawa et al, 2005a).

3.4.4 Topical areas of discussion

Findings of the observational studies of (recorded) accompanied adult patient interactions suggest that companions may be more heavily involved in some topical areas of medical visit discussions than others.

Tsai (2000) divided consultations into 'information-providing cycles' (defined as information provided by the patient and/or companion and related to the patient's health) and 'non-information-providing cycles' (that included all other types of information). The author found that patients contributed significantly more (approximately twice as much) than companions to information-providing cycles ($p < 0.003$). The author observed that companions contributed slightly (but not significantly) more to 'non-information-providing cycles' than patients did. However, patients were significantly more likely than companions to volunteer 'information-providing cycles' ($p < 0.01$).

Tsai (2000) classified the content of 'information-providing cycles' into five categories; of these, biomedical information (42%) and management information (37%) were the categories most frequently observed, followed by daily routines and personality information (11%), pedigree information (10%), and physical exam information (0.5%). Patients were found to be the primary providers of information across all five categories. However, topically, only patient provision of biomedical information ($p < 0.0001$) and daily routine and personality information ($p = 0.037$) were significantly greater than companion provision. Suggesting that management information ($p = 0.163$) and pedigree information ($p = 0.315$) was provided more equally by patients and companions. Management information referred to patient resources for managing their health

problem and pedigree information referred to family tree, hereditary factors, marital status and family living arrangements.

Similarly, Ishikawa et al (2005a) found that companions gave less biomedical information than patients did in accompanied interactions ($p < 0.001$). In addition, Eggly et al (2006) explored the frequency and topic of question asking in accompanied interactions and observed that treatment, diagnostic testing, diagnosis, and prognosis were the most frequently occurring topics for both patients and companions. Of these topics, companions were found to be particularly active in diagnostic testing discussions (Eggly et al, 2006). In addition, Ellingson (2002) reported that companions performed more active roles in encounters when mental health and medication topics were raised. Finally, Clayman et al (2005) observed that 21% of companions in their data prompted patients to discuss topics, and one third of companions introduced medical topics not previously discussed by the patient or doctor.

3.4.5 Participant behaviours and patient outcomes

Most of the observational studies of (recorded) accompanied adult patient interactions identified in the review explored the interactive dynamics of participant behaviours in accompanied interactions.

Street and Gordon (2008) observed that patients in their data were generally more verbally active participants than their companions. However, when they analysed participation as a proportion of participant talk, a significantly greater proportion of companion talk was defined as 'active' participation ($p < 0.001$). This suggested that when companions did speak it was to actively participate (ask questions, express concerns, state an opinion or preference) (Street and Gordon, 2008). Likewise, other studies have reported that significantly more question asking takes place in accompanied interactions (Eggly, 2011). This difference could be attributed to companions, who have been observed to ask significantly more questions than patients in accompanied interactions (Eggly, 2011 and Ishikawa et al, 2005a).

Companions have also been observed to volunteer information or respond to doctors' questions when they have not been invited (by the doctor) to do so. Beisecker (1989) found that companions in her data directed more comments to

doctors than doctors did to companions, indicating that companions initiated or responded to comments when the doctor was not addressing them. Furthermore, Greene et al (1994) observed that companions answered for the patient at least once in 73% (11) of the visits observed, even though the patient was capable of doing this himself or herself. In addition, the authors found that doctors and companions often talked about older patients rather than with them (using pronouns such as 'she' or 'he'); doctors were observed to do this an average of 12 times per visit and accompanying persons an average of 18 times per visit. Moreover, patients in the accompanied interactions were observed to be significantly less assertive ($p < 0.001$) and expressive ($p < 0.01$) compared to patients that attended alone (Greene et al, 1994).

Finally, Tsai (2000) observed that ordinarily only one of the patient party (patient or companion) volunteered information or responded to the doctor's information-eliciting acts ($p < 0.01$). The author found that patients were significantly more likely to respond to the doctor's questions alone and provide a sole answer (45%) compared to companions (15%) ($p < 0.01$). However, the author also reported that companions participated in 359 'information providing cycles', but that only 36% of their contributions were made in response to initiations by others, whereas 62% of their contributions were classified as volunteered. This suggested that much of the companions talk was not invited.

However, authors have also shown that companion contributions enhance patient autonomy (Clayman et al, 2005), facilitate doctor-patient discussions (Gilliam et al, 2009 and Clayman et al, 2005), and proportionally more companion talk has been classified as supportive rather than detractive (Ishikawa et al, 2005a).

In an observational study of patients with epilepsy, their companions (when present), and community-based neurologists, Gilliam et al (2009) observed that the interactions involving a companion resulted in lengthier, more detailed discussion of medication side effects. In addition, the authors reported that companions helped to facilitate doctor-patient discussions by providing additional information about side effects from a neutral perspective, and helped to track changes in patient symptoms over time.

Furthermore, Clayman et al (2005) found that companions in their data engaged in significantly more patient autonomy enhancing behaviours than they did patient autonomy detracting behaviours. Autonomy enhancing behaviours included facilitating doctor understanding, clarifying or expanding history, introducing medical topics, facilitating patient understanding, repeating doctors' explanations, asking doctors questions, facilitating patient involvement, prompting patient to discuss topics, asking patients questions, and asking patients to express opinions. Autonomy detracting included being controlling toward the patient, answering for the patient, repeatedly interrupting the patient, discussing their own health problems, belittling patient, insulting patient, and expressing 'expert' opinions, for example, '*I told you so*'. The authors found that 52% of companions in the data engaged in at least one autonomy enhancing behaviour and did not display any autonomy detracting behaviours and 41% of companions engaged in at least one behaviour of every kind (autonomy enhancing and detracting). However, no companions engaged in only autonomy detracting behaviours.

Similarly, Ishikawa et al (2005a) reported that more companion talk in their data helped or supported the patient (8%) than it did criticize the patient or persuade the patient to take a particular course of action (2%).

In addition, a handful of the observational studies identified explored the effects of companionship on emotional expression. Companions have been observed to express significantly less emotion than patients in accompanied interactions (Ishikawa et al, 2005a). However, the results of differences between patient emotional expression in accompanied and unaccompanied interactions are mixed. Wolff and Roter (2012) and Ishikawa et al (2005a) reported that patients in dyadic interactions contributed significantly more positive talk than patients in accompanied interactions did, whereas Street and Gordon (2008) observed that that unaccompanied patients expressed significantly more negative feelings than accompanied patients did.

Authors have also examined the effect of the presence of a companion on doctors' communication styles. Street and Gordon (2008) observed that doctors' use of facilitative communication was not significantly associated with the presence of a companion. In addition, Greene et al (1994) found that the

presence of a companion was not associated with differences in doctor responsiveness (the quality of question asking, information giving and supportiveness). However, other studies have found that doctors engaged in significantly less question asking (Wolff and Roter, 2012), partnership-building (Wolff and Roter, 2012 and Ishikawa et al, 2005b), and joint decision-making (Street and Gordon, 2008) in accompanied interactions.

In terms of topical areas of discussion raised by doctors, Greene et al (1994) observed no significant difference between the content of topics raised by doctors in accompanied and unaccompanied interactions. However, accompaniment has been observed to hinder (decrease) doctors' responses to patients' emotional cues (Oguchi et al, 2010). In addition, Labrecque et al (1991) observed that doctors were significantly less likely to provide emotional support to accompanied patients and to (non-symptomatic) patients attending alone.

Finally, the presence of a companion has been positively related to informed decision-making (Clayman et al, 2005) and patient satisfaction outcomes (Street and Gordon, 2008). Other studies report no significant differences between accompaniment status and patient-centeredness and satisfaction (Shields et al, 2005) or patient-centred communication outcomes (Wolff and Roter, 2012); that is, they do not report a negative effect.

4. Discussion

The results of this review suggest there is a deficit of research exploring accompanied interactions with 'working age' adult patients (18 to 60-65 years of age) and adult patients of 'all ages' (over 18 years of age). Nearly two-thirds of the 51 studies identified for inclusion in this review involved child patients (under 18 years of age) or older patients (over 60-65 years of age) and their companions. Less than 23% of the 51 studies identified explored accompanied interactions with adult patients of 'all ages' (over 18 years of age). However, this is perhaps to be expected given that the findings of the review suggest that children and older patients are the largest groups of patients routinely accompanied to medical appointments.

Notably, of the (twelve) studies that explored accompanied 'all age' adult patient interactions, most (over three-quarters) focused exclusively on 'disease specific' populations. Eight of the studies explored interactions with adult cancer patients (Eggly et al, 2011; Cordella, 2011; Oguchi et al, 2010; Street and Gordon, 2008; Eggly et al, 2006; Beisecker et al, 1997; Beisecker and Moore, 1994 and Labrecque et al, 1991), one examined the experiences of diabetes and heart failure patients (Rosland et al, 2011) and one examined patients with epilepsy (Gilliam et al, 2009).

Quantitative methods were used in nearly two-thirds of the 44 empirical studies and in over 50% of the 31 observational studies identified for inclusion in the review. Similarly, Charon, Greene and Adelman (1994) have observed that quantitative methods have been used most widely in the analysis of doctor-patient interactions. The majority of the 31 observational studies discussed here that used quantitative methods (over two-thirds) used process analysis methods (typically RIAS or modified RIAS methods). In a review of the paediatric literature, Tates and Meeuwesen (2001) also reported that the most popular approach to analysis of accompanied medical encounters involved quantitative (process analysis) methods, including use of the RIAS.

However, a number of concerns have been raised about using process analysis to analyse triadic interactions (and doctor-patient interactions more generally). Process analysis has been criticised for placing too much emphasis on outcomes (Charon, Greene and Adelman, 1994); for example, on patient compliance, utilisation of health services, satisfaction, and/or the functional status of participants. Authors have observed that a preoccupation with outcome measure-linked behaviours may limit process analysis to telling half a story, with other important behaviours discounted from the analysis (Charon, Greene and Adelman, 1994). Similarly, Cahill and Papageorgiou (2007a) have suggested that because most process analysis methods do not assume a connection between why people talk, what they talk about, and how they talk, they do not identify the overall content of communication. Likewise, Charon, Greene and Adelman (1994) have criticised process analysis systems for their exhaustive list of behaviour categories, which are usually mutually exclusive, and do not allow for analysis of the multiple functions that the unit of analysis may simultaneously fulfil (often focusing on the primary function alone). Similar criticisms have been levelled at content analysis methods. Cahill and

Papageorgiou (2007a) have highlighted the inherent complications of coding triadic interactions and have concluded that much of the complexity may be lost in the analysis.

Nevertheless, a variety of different variable and outcome measures were used in the process analysis studies included in this review. Many authors used modified versions of the Bales (IPA) or RIAS systems of analysis, which were adapted and expanded to suit their particular aims and objectives. In addition, some authors used qualitative approaches (discourse analysis, grounded theory or other microanalytic methods) to identify variables of interest and quantified these. Therefore, it appears that these quantitative (process and content analysis) methods are by no means static; many authors applied specifically developed schemata in their analyses.

Nine observational studies were identified in which qualitative methods were used, three of these used CA methods to analyse data and the remainder used other qualitative (sociolinguistic, discourse analysis, or combined), predominantly microanalytic, methods. Studies that use microanalytical methods pay particular attention to the structure, form and sequence (turn-taking) of information exchanged (Charon, Greene and Adelman, 1994). Given the attention to detail, microanalysis may be the method of choice to fully understand accompanied interactions.

However, there may be disadvantages to using a microanalysis as the main approach of inquiry in the study of accompanied interactions. Microanalytic methods have been criticised for focusing on 'process' and paying too little attention to the actual content of participant behaviours (Ong et al, 1995). Authors have also pointed out that microanalytic studies tend to forego representativeness (be smaller) and generalization (beyond commonalities) (Charon, Greene and Adelman, 1994). In addition, Bensing, van Dulmen and Tates (2003) have reported that real breakthroughs in knowledge require systematic testing, and that it can be argued that microanalysis (and other qualitative methods) alone is too time-intensive and lacks the generalizability to achieve this.

Given the pros and cons of the methods described, it is unclear which methods are best suited to analyse accompanied interactions. As Charon, Greene and

Adelman (1994) have reported, and as the discussion here suggests, researchers exploring triadic medical interactions have to make difficult choices.

Microanalytic methods allow researchers to analyse encounters in considerable detail, but these methods may fail to generate findings applicable to other audiences and are very time intensive. On the other hand, quantitative (especially process analysis) methods allow researchers to analyse large datasets and may generate findings beyond commonalities. However, these methods may limit or exclude analysis of the organisation, structure, meaning and wider context of interactions and be predisposed to the analysis of behaviours as linked to specified outcomes.

It is not surprising then that researchers have called for methods that include multiple approaches in order to study the multiple levels at which exchanges of meaning occur; including analysis of the context, sequence of interaction, form and content of interactions (Coe and Prendergast, 1985).

Considering this, it was reassuring that a number of observational studies of accompanied adult patient interactions identified in this review (n=6, approximately one-fifth) used mixed methods to analyse data. Of these, only one study (van Staa, 2011) used a mixture of discrete (quantitative and qualitative) methods. Most of the 'mixed method' studies identified used combined methods that fell somewhere between micro and quantitative analysis methods (Cordella, 2001; Tsai, 2000; Aronsson and Rundstrom, 1988; Greene et al, 1994 and Tates and Meeuwesen, 2000).

The Turn Allocation System (TAS) appears to be particularly promising method to bridge the microanalytic – process analysis methodological divide. The TAS was the only method identified in the review that was observed to quantify interaction sequences beyond two-part turns, and incorporated microanalytic (CA) and process (including content) analysis methods (Aronsson and Rundstrom, 1988 and Tates and Meeuwesen, 2000).

As reported by other authors (for example, Street and Millay, 2001), the most popular approach to data collection in the empirical studies identified for inclusion was to audio or video-record encounters. 17 studies were identified for inclusion that analysed audio or video recordings of accompanied adult patient

interactions (this number does not include four observational studies that examined dementia, memory problem and Alzheimer's disease patient groups).

The findings from these studies suggest that, despite the presence of a companion, patients remain the primary providers of information in accompanied interactions (Tsai, 2000). Moreover, despite accompanied patients occupying significantly less discourse space than unaccompanied patients, companions have been observed to occupy significantly less discourse space than patients in accompanied encounters (Wolff and Roter, 2012; Street and Gordon, 2008; Ishikawa et al, 2005a and Sheilds et al 2005). Patients have also been observed to contribute more information than companions in all topical areas of discussion (Tsai, 2000), especially bio-medical information (Ishikawa et al, 2005a).

Furthermore, the strongest coalition in accompanied interactions has been observed to be the patient-doctor alliance (Coe and Prendergast, 1985). However, it is notable that in non-participant observation and survey based studies authors have not observed any great frequency of the coalitions proposed by Coe and Prendergast (1985), suggesting they do not feature heavily in encounters (Hasselkus, 1992), or are so subtle that participants may not recognise or recall them (Beisecker et al, 1996). Adelman, Greene and Charon (1987) have observed that coalitions are, by definition, not present when the accompanying person is a passive participant. Thibaut and Kelley (1959) have also reported that coalitions do not always form in triads when there is agreement on the desirability of goals. Therefore, the relative deficit of coalitions observed in accompanied interactions may be a consequence of companions being passive participants, or the mutual alignment of participant goals in these encounters.

The analysis of companion roles was identified as a particularly active research area. Authors have reported that companions occupy a number of different roles in accompanied encounters; and the accompanying person has typically been observed to occupy multiple roles within the bounds of a single consultation. Although a minority of companions have been observed to assume 'oppressive' or 'domineering' roles, the majority of companions have been reported to occupy 'caring', 'partnership' (Cordella, 2011), 'passive' (Street and Gordon, 2008) and 'advocate' roles (Street and Gordon, 2008; Ishikawa et

al, 2005) the majority of the time. Likewise, authors of survey-based research have reported that doctors most frequently describe companions as occupying 'advocate' or 'observer' roles (Brown et al, 1998).

It is also notable that authors have reported that, despite some discrepancies, accompanying persons usually align their participation with the needs and preferences of the patient. Ishikawa et al (2005a) observed that when patient expectations of the companion were higher the companion was more verbally active, gave more information and asked more questions. When patients had higher expectations of an indirect companion role, the companion was less verbally active and more supportive of patient talk.

However, authors have also observed that when companions do contribute, their talk is more 'active' than that of patients (Greene et al, 2004). Companions have been shown to express concerns, direct comments to doctors (Beisecker, 1989) state opinions or preferences (Street and Gordon, 2008) and ask questions (Street and Gordon, 2008; Eggly, 2006 and Ishikawa et al, 2005a) more frequently than the patients they accompany. Likewise, authors have reported that a greater proportion of companion talk is volunteered (Tsai, 2000). In addition, authors have observed that companions sometimes answer on behalf of patients (Beisecker, 1989 and Greene et al, 1994). Correspondingly, patients have been observed to be significantly less expressive and assertive in accompanied interactions (Greene et al, 1994).

However, these companion behaviours do not necessarily detract from patients' autonomy. Indeed, a number of studies found that companion contributions enhanced patient autonomy (Clayman et al, 2005), were generally supportive of the patient (Ishikawa et al, 2005a) and helped facilitate doctor-patient interaction (Gilliam et al, 2009 and Clayman et al, 2005).

Therefore, many of the companion behaviours observed in medical visits may be aligned with advocating for the patient and ensuring courses of action are in the patient's best interest. For example, companions have been found to be particularly active in discussions centred on diagnostic testing (Eggly et al, 2006), health management (including medication) (Ellingson, 2002; Tsai, 2000 and Gilliam et al, 2009), mental health (Ellingson, 2002 and Gilliam et al, 2009), and family contexts (including, hereditary factors, marital status and family living

arrangements) (Tsai, 2000). It is also notable that companions have been observed to raise topics, and prompt patients to discuss topics, not previously mentioned by the doctor or patient (Clayman et al, 2005 and Cordella, 2009).

These findings appear to reflect the fact that a lot of information discussed in medical encounters (for example, bio-medical information) may be the privileged epistemic domain ('self-knowledge') (Heritage, 2012) of patients. Findings from the literature appear to suggest that companions have greater involvement in discussions when they have valuable information to add, and where decisions may have impending consequences for the patient (and to an extent, the companion). For example, with regard to preferences about diagnostic testing, the perceived or witnessed effects of treatments, the mental health of patients, health management resources (in which companions may be intimately involved), and family contexts (of which the companion is likely to be part).

The presence of a companion has also been associated with changes in doctors' communicative styles. However, no significant changes in doctors' use of facilitative communication (Street and Gordon, 2008) and responsiveness (Greene et al, 1994) were observed in the studies of accompanied interactions included here. However, research has identified that doctors engage in significantly less question-asking (Wolff and Roter, 2012), partnership-building (Wolff and Roter, 2012 and Ishikawa et al, 2005a) and joint decision-making (Street and Gordon, 2008) in accompanied interactions.

However, if companions are more 'active' in their talk (including asking the doctor questions, prompting the patient to discuss topics, and raising new topics), it may be the case that doctors do not need to ask as many questions in accompanied interactions. Likewise, the presence of a companion may reduce the need for doctors to engage in partnership-building and joint decision-making activities with accompanied patients, as some of these functions may be stimulated by the presence of a companion or shifted to the patient-companion domain. Similarly, doctors have been observed to be less receptive to patients' emotional cues (Oguchi et al, 2010) and provide less emotional support to patients when a companion is present (Labrecque et al, 1991). However, if the companion offers this support, the need for doctors to be receptive to patients'

emotional cues and to offer this support may be reduced. Furthermore, patients may prefer that companions, as opposed to doctors, fulfil these functions.

Authors have also observed that the presence of a companion was not detrimental to a number of patient outcomes. Authors have reported no significant effect of companionship on patient-centeredness (Shields et al, 2005) and satisfaction (Shields et al, 2005 and Labrecque et al, 1991) or patient-centred communication outcomes (Wolff and Roter, 2012), or they have found that the presence of a companion positively enhances informed decision-making (Clayman et al, 2005) and patient satisfaction outcomes (Street and Gordon, 2008).

Finally, only two of the studies identified for inclusion in this review reported a significant difference in the duration of unaccompanied and accompanied interactions (Ishikawa et al, 2005 and Labrecque et al, 1991) and the rest did not (Wolff and Roter, 2012; Street and Gordon, 2008; Shields et al, 2005; Greene et al, 1994 and Beisecker, 1989). Given these discrepancies, it is tentatively concluded that accompanied interactions are typically marginally (but not significantly) longer than unaccompanied interactions.

4.1 Comparability of studies

This review has identified a number of observational studies that have explored accompanied adult patient interactions. However, as is evident in the results (and discussion) section(s) of this chapter, a number of divergent results emerged from the literature. It appeared important that the possible reasons for the variance of these results be examined.

The studies identified for inclusion in this review used a variety of different methods to analyse accompanied patient interactions. However, it is difficult to know to what extent the results of studies that have used different methods, participant samples, in different clinical settings, and that have been conducted at different times are comparable.

As a case in point, the results of studies that have explored participant discourse spaces in this review broadly align with those presented in a recent meta-analysis conducted by Wolff and Roter (2011), in which the results of

three studies (Ishikawa et al, 2005a; Street and Gordon, 2008 and Shields et al, 2005) were combined. However, there appears to be strong methodological grounds for not combining the results of these studies and/or for treating the combined results with caution.

For example, Ishikawa et al (2005a) reported the results of two different triadic encounters, a 'typical' triad consisting of a patient, doctor and companion (who was not a patient) and a 'double-patient' triad consisting of a doctor and two patients (who were both 'seen' in the consultation). Significant differences were observed between participant characteristics for the two accompanied groups. However, the authors (Ishikawa et al, 2005a) combined these two different 'triad samples in their participant discourse space analysis. These (combined) results were subsequently used in Wolff and Roter's (2011) meta-analysis.

In addition, of the 84 accompanied patients participating in Street and Gordon's (2008) study, 82% (69) were accompanied by 1 person (69% female, 11% male, and 2% unknown), 14% (12) were accompanied by two companions and 4% (3) were accompanied by more than two companions. In contrast, the accompanied interactions in the other two studies (Ishikawa et al, 2005 and Shields et al, 2005) were purely triadic (three person).

Moreover, the 30 patients participating in Shields et al's (2005) study were randomly assigned to be accompanied (13) or unaccompanied (17). It is unknown whether this had an effect on the verbal activities of patients and their companions in the encounters. However, it is notable that of the 63 (51%) patients who refused to participate, most cited their unwillingness to change the manner in which they came to see the doctor as the reason for non-participation. Furthermore, companions were found to occupy just 8% of the discourse space in these encounters; considerably lower than the 15% reported by Street and Gordon (2008) and the 22% reported by Ishikawa et al (2005a).

It is also notable that each of these studies took place in different clinical settings and contained different patient groups. Shields et al (2005) studied older adults in community and hospital based general practice settings in the US, Ishikawa et al (2005a) studied elderly adults in hospital based general practice in Japan and Street and Gordon (2008) studied adults of 'all ages' (over 18 years of age) in a specialist outpatient oncology department in the US.

Hence, the extent to which these studies are comparable, and the results can be combined, appears limited.

The setting of studies appears to be a particularly important factor when considering the comparability studies. Of the studies included in this review, some took place in primary care, some in secondary care, and some took place in specialist care settings (across community, general practice and hospital based environments). In addition, studies were conducted across a number of different countries. These factors are important to consider, as study settings are not always transferrable. For example, primary care consultations may be considerably different to secondary and specialist care consultations (in terms of problem presentation, format, structure, duration, etc.) In addition, studies may have been undertaken in different countries, with disparate cultures and healthcare systems (Cahill and Papageorgiou, 2007a).

Differences in results may even be apparent across similar services located in different areas. There may be significant differences in the numbers of patients accompanied and the reasons that patients are accompanied in similar clinical settings across different geographical areas. For example, transportation has been identified as one of the main reasons patients are accompanied to primary care medical visits in rural areas (Glasser, Prohaska and Gravdal 2001 and Glasser and Prohaska, 1999).

This review tentatively concluded that accompanied interactions are not significantly longer than unaccompanied interactions. However, this conclusion goes against the finding of Wolff and Roter's (2011) meta-analysis. Pooling the effect size and significance of studies that examined the length of 'routine' adult accompanied and unaccompanied medical interactions (n=6), the authors found that accompanied visits were significantly longer (mean 29.8 minutes, ± 21.4) than unaccompanied visits (mean 24.6 minutes, ± 19.1) ($p < 0.01$).

However, the extent that it made sense to combine the results of these studies (in a meta-analysis) or directly compare the results of these studies (as was done to a limited extent here) is questionable. For example, the studies included in Wolff and Roter's (2011) meta-analysis took place in different clinical (oncology, primary care and specialist) settings. The individual studies included in the meta-analysis also used a range of measurements to calculate

consultation duration (for example, minutes, words, turns, statements, etc.) In addition, three of the studies reported the results of initial consultations, which Labrecque et al (1991) has suggested constitute unique interactions, and the remainder explored follow-up visits. Taken individually, the results of the studies included in the meta-analysis (Wolff and Roter, 2011) present a mixed picture (similar to the findings presented in this review) of differences between the duration of unaccompanied and accompanied patient visits. Some of the studies reported a significant difference in duration and others no significant difference.

Similarly, it is important to consider the different patient samples of studies included in this review. Alongside differences in study methodologies and settings, these differences may help to explain disparities between the results presented. Most of the observational studies of (audio or video recorded) accompanied adult patient interactions analysed in this review (n=10) included older adult patient samples (over 60-65 years of age), only seven studies included adult patients of 'all ages' (over 18 years of age).

As Gabe et al (2004) have pointed out, tentative power relations exist between the professional responsibility of healthcare agents and institutions and the role of the family and other informal caregivers. This is congruent with Beisecker's (1989) observation that the accompanied medical encounter forms a juncture between the family care system and the professional care system. It is also worth considering that decisions in healthcare may have profound consequences for family members (and carers) as well as the patient (Gabe et al, 2004). As Bensing, van Dulmen and Tates (2003) have noted, doctors need to consider the viewpoints of family members (carers) as well as those of the patient.

The asymmetry of doctor-patient interactions has long been a core focus of medical discourse research (Byrne and Long, 1976 and Mishler, 1984). However, this is not the only relationship in an accompanied encounter, and asymmetry may be compounded in some patient groups. For instance, the child patient has been observed to face a 'double asymmetry', the institutional authority of the doctor and the status of the parent (Tates and Meeuwesen, 2001).

Variations in power imbalance may exist among patients and accompanying persons, dependent upon the nature of their relationship and the wider social structure in which they operate. It is likely that more asymmetry is experienced by some patient groups (for example, older and elderly patients) more than others (for example, younger adults); older and elderly patients may be more dependant on others (including accompanying persons) for their care needs. In addition, doctors' assumptions about the competence and level of understanding of patients should also be considered. For example, authors have reported that doctors may assume the decision-making authority of older and elderly patients has been delegated to others, when it has not (Clayman et al, 2005).

The reason for the visit and/or patient diagnosis may also help to explain some of the variance of results observed in this review. Six of the seven observational studies that explored 'all age' (over 18 years of age) accompanied adult patient interactions (and used audio or video recorded data) investigated the experiences of adult cancer patients (and took place in secondary or specialist care settings). The results of studies in these settings may be significantly different from those in other settings. Patient diagnosis (or the reason for the visit) is likely to have a substantial impact on the clinical encounter. For example, patients may have a (chronic) condition that they may consider themselves 'experts' at managing and want to be autonomous in their decision making; negotiating with healthcare professionals to achieve the outcomes they desire. On the other hand, patients facing life threatening conditions may want to allow healthcare professionals more, or complete control of decision making processes.

The year(s) in which the studies were conducted may also impinge on the extent that they can be compared; for example, some studies presented in this review were conducted in the late 1980's, others were conducted as recently as 2012. Power alignments in triadic interactions, as in society, are not the consequence of participant behaviours alone. As Gabe et al (2004) have observed, the foundations of these power alignments extend much deeper, and these relationships have to be considered beyond the asymmetry of traditional doctor-patient interactions or the balance of power in interpersonal relationships between patient and accompanying persons.

It is recognised that the power differentials between participants and the individual perspectives and experiences of participants help shape accompanied medical encounters. However, authors have noted that social contexts and the organisational and legal frameworks that shape these encounters also need to be acknowledged (Gabe et al, 2004; Tates and Meeuwesen, 2001 and Cahill and Papageorgiou, 2007a). For example, broader social change and policy drives, such as 'partnership' and the push towards 'patient centeredness' and 'shared decision making' that arose during the late 1990's as a result of the UK Labour government's modernization agenda for the NHS (Gabe et al, 2004). In addition, authors have recognised that there has been an increasing emphasis on 'informed consent' over this period (Tates and Meeuwesen, 2001).

Authors have reported that the establishment of these frameworks and shifts in medical and social care policy and cultures have helped to determine acceptable behaviours and the content of medical interactions (Gabe et al, 2004). These frameworks and 'legal underpinnings' need to be considered against broader social changes that inspire policy shifts or are created as result of them. As Tates and Meeuwesen (2001) have observed, the nature of the doctor-patient relationship has changed considerably in recent decades, from one that is very asymmetrical to one that is more egalitarian, emphasized by the increased autonomy of patients. As well shifts in policy, the culture of medicine has had to align with broader social changes. As Fortinsky (2001) has noted, medical culture increasingly has to recognise patients as 'consumers', patients as 'experts', the uncertainty in medical science and practice, and the wealth of medical information now available via the Internet. These factors may all have a bearing on the variability (and comparability) of the results presented in this review.

Finally, researchers need to pay attention to sample bias. The observation of medical encounters is likely to limit the generalizability of findings in a number of ways. For example, given the nature of the data and the organisations in which data are collected, most data are collected using opportunistic sampling methods. This is a problem in itself. There are likely to be differences in persons (patients, accompanying persons and doctors) who agree to participate in observational studies, and those who decline. In addition, as Cahill and Papageorgiou (2007a) have commented, those that choose to participate may

vary their behaviour as a consequence of observation, being unusually quiet or making an unusual effort to talk. However, as the authors have observed, these types of selection bias needs to be considered, but are probably impossible to avoid.

5. Limitations

The generalizability of findings from this review are limited in a number of respects.

It is acknowledged that this review was comprehensive, but not systematic. In addition, just one (albeit large) research database (ISI Web of Knowledge) was searched. In addition, a number of inclusion and exclusion criteria were applied. There may be important data absent from this review as a result of the search strategy used and the inclusion and exclusion criteria that were imposed.

For example, studies taking place in psychiatric, psychology, couple or family therapy, emergency room and end of life (palliative care) settings were excluded entirely from this review. However, as was discussed, various authors have considered interactions that take place in these settings as unique / distinct from those that take place in other medical settings (see Methods, Exclusion criteria). It is also worth noting that studies were not excluded from the review if they included patients (in other medical settings) that, for example, experienced mental health problems or had terminal illnesses. Nevertheless, it is acknowledged that some types of encounters excluded from this review, for example, those that took place in psychiatric and psychology settings, may have provided additional insights as to the effects of the presence of companions in accompanied interactions.

Similarly, studies taking place in paediatric, Alzheimer's disease, dementia or memory clinic settings were excluded from the fourth stage of analysis in the review: 'the effects of the presence of companions' (see Methods, Data extraction and analysis). However, prior to their exclusion, these studies were examined to determine the broad methodological perspective used, the age range of the patient sample(s), the proportion of patients accompanied to visits, patient and companion characteristics, and (in the case of those studies using observational methods) the specific methods used to analyse data.

Moreover, one of the main goals of this review was to identify studies that used data akin to that gathered in the seizure clinic (recorded interactions with accompanied adult patients). Had all studies that have explored accompanied medical interactions been included in this review and analysed in their entirety, much of the data generated may not have been relevant to accompanied adult patient interactions and outcomes.

In much the same way, it was observed that all conceptual frameworks, literature reviews and meta-analyses identified for inclusion in this review were limited to certain patient groups or medical settings. In their reviews, Beisecker (1996) and Adelman, Greene and Charon (1987) only included/considered studies of older adult patients. Fortinsky (2001) focused on older adult patients with dementia. Street and Millay (2001) only considered adult patient interactions in their conceptual framework. Gabe et al (2004) focused on paediatric encounters in their conceptual framework. Tates and Meeuwesen (2001) only included studies of audio or video recorded encounters with children and caregivers in their literature review. Cahill and Papageorgiou (2007a) only included studies that explored encounters with children aged 6 to 12 that were considered relevant to primary care in the UK in their literature review. Finally, Wolff and Roter (2011) only included studies that examined encounters with adult patients where quantitative information regarding patient accompaniment and patient or family companion attributes, visit structure, communication processes, and/or outcomes of care were presented (studies of paediatric patients, hospitalized or terminally ill patients, and studies of interactions that took place in emergency room, end-of-life care, genetic counselling, and mental health (psychiatric) settings were excluded).

6. Conclusion

In conclusion, the results of this review suggest that there is a deficit of research exploring younger and 'all age' accompanied adult patient interactions; especially outside of oncology settings.

The findings indicate that there is considerable variance in the results of observational studies that have explored accompanied adult patient interactions. These differences may be due to differences in methodologies, study settings (for example, primary, secondary or specialist care settings, rural or urban settings, and country of origin), the nature of consultations (for example, initial, routine or follow-up visits), patient samples (for example, age, diagnoses, care needs), accompanying person characteristics (for example, relationship to the companion), and when the studies were conducted (with regard to changes in social, cultural, institutional frameworks over time). These differences may mean that the generalizability of these findings is likely to be limited, and that findings from these studies should be compared with caution.

Despite this variance, this review tentatively concludes that the presence of a companion is ordinarily associated with no difference in patient outcomes, or the enhancement of patient outcomes. It appears that the doctor-patient relationship remains key in these interactions, and the presence of a companion may result in positive benefits for patients (and doctors), with negative consequences only observed in a minority of cases.

This review examined the methods used to analyse accompanied patient interactions, and a variety of methods were identified. Of these, process analysis methods (especially the RIAS) were the most widely used. There appears to be a deficit of observational studies that use qualitative and mixed methods to explore accompanied patient interactions.

Methodologically, this review concludes that communication must be studied in the broader context of the aims and targets of the study (as proposed by Bensing, van Dulmen and Tates, 2003). Beyond this, it is suggested that flexibility is key – methodologies should not simply be applied because of perspective or comfort. A number of observational studies were identified in the review that used a variety of measures and units of analysis to explore

accompanied interactions, and it is argued that the needs of the study should ultimately dictate the methods used to analyse these interactions.

The author particularly welcomes the use of combined methodologies and mixed-method frameworks. However, it is noted that developing appropriate research methods to analyse accompanied medical interactions is not easy. As Roter and Larson (2002) have suggested, this necessitates bridging the schism between qualitative and quantitative methods, crossing domains, and moving beyond what has been comfortably done in the past.

The next phase of this research project helps to address the deficit of observational studies that have explored medical encounters with accompanied adult patients of 'all ages' (over 18 years of age). Findings from this review, particularly the methodological and theoretical perspectives of authors, helped to inform the approach to analyses in the next phases of study.

Adopting a mixed method framework, 50 encounters with seizure patients (and where applicable, their companion) and neurologists were analysed. In the next chapter of this thesis (chapter five) quantitative methods were used to explore differences between the duration and discourse spaces of participants in unaccompanied (dyadic, doctor and patient) and accompanied (triadic, doctor, patient and companion) neurology clinic encounters. In chapter six, the discourse spaces, linguistic and interactive behaviours, and topical content of participants talk in accompanied outpatient interactions were explored using quantitative and mixed qualitative (microanalytic) methods. The results of studies identified for inclusion in this review were (cautiously) considered (where appropriate) against findings from these analyses.

Chapter five: Duration and structure of initial (diagnostic) accompanied and unaccompanied neurology outpatient encounters

1. Introduction

Studies focusing on the risk of misdiagnosis underline the importance of obtaining accounts not only from patients, but also from witnesses of attacks (Leach et al, 2005 and Smith, Defalla and Chadwick, 1999). Consequently, seizure patients that attend initial diagnostic consultations are routinely invited to bring along a companion to their appointment. However, little is known about the proportion of patients accompanied to seizure clinic visits, especially to initial consultations. In addition, the effects of companionship on patients' contributions to these consultations have not been previously explored.

The effects of patient companionship, on the other hand, have been studied in a variety of other clinical settings. As described in the previous chapter (four), a number of positive effects have been described. Companions have been observed to help facilitate doctor-patient discussions (Gilliam et al, 2009 and Clayman et al, 2005) and enhance patient autonomy (Clayman et al, 2005). The presence of a companion has also been associated with improved patient outcomes (Wolff and Roter, 2011), such as informed decision-making (Clayman et al, 2005) and higher levels of patient satisfaction (Street and Gordon, 2008).

However, previous studies also highlight potential negative effects of companions on doctor-patient interactions. For instance, it has been demonstrated that the presence of companions significantly reduces the discourse space (the proportion of words spoken by a particular participant to the total number of words spoken by all participants in the interaction) available to patients (Wolff and Roter, 2011; Street and Gordon, 2008; Ishikawa et al, 2005a and Shields et al, 2005). Furthermore, whilst the average verbal activity of companions reported in the literature is considerably less than that of patients, companion contributions have been shown to vary across different clinical settings and patient groups (Wolff and Roter, 2011; Street and Gordon, 2008; Ishikawa et al, 2005a and Shields et al, 2005).

In relation to initial (diagnostic) seizure clinic visits, this means that the obvious benefits of having access to a companion's account could be reduced by the loss of diagnostically important information associated with the reduction of the patient's discourse space.

Loss of patient discourse space in these interactions is particularly relevant. A number of recent studies (as described in chapter two) have demonstrated how different sociolinguistic techniques can improve diagnostic accuracy and the doctor's understanding of patients' experience of their condition (Guelich and Schoendienst, 1999; Schoendienst, 2001; Furchner, 2002; Surman, 2005, cited in Schwabe et al, 2008; Schwabe, Howell and Reuber, 2007; Plug, Sharrack and Reuber, 2009a, 2009b, 2009c and Reuber et al, 2009). These studies were based on the analysis of clinical interviews in which doctors talked to unaccompanied patients with seizures. In these encounters, patients were given time and discourse space to talk about what was most relevant to them. Using the 'EpiLing' method, doctors were expected not to interrupt patients or to introduce new topics (at least in the early parts of these encounters) (Schwabe, Howell and Reuber, 2007 and Schwabe et al, 2008).

1.1 Aims and objectives

The main aim of this study was to assess how the presence of a companion affected patient discourse space. If the discourse space of patients accompanied to initial (diagnostic) seizure-clinic visits was significantly reduced, a hypothesis could be proffered that this reduction may result in the loss of diagnostically important information associated with *how* patients describe their attacks. To this end, the proportion of patients accompanied to visits, differences between the duration and 'structure' of unaccompanied (dyadic: patient and physician) and accompanied (triadic: patient, physician and one companion) interactions, and companion contributions to patient-party talk were explored. The term 'structure' is used here to convey the 'make-up' of consultations in terms of participants discourse spaces.

The study also aimed to advance what is known about 'structural differences' in these types of interactions; that is, differences and correlations between participants discourse spaces. The strength, direction and significance of correlations between patient-companion and patient-doctor discourse spaces

were explored to see to what extent changes in the discourse spaces of companions and doctors were associated with changes in the discourse spaces of patients (and vice-versa). As part of this analysis, correlation of doctor-companion discourse spaces was also examined. No known studies had previously explored accompanied and unaccompanied interactions using these methods.

2. Methods

2.1 Data collection

Between January 2010 and March 2012, 50 patients (aged over 18 years) attending a specialist outpatient seizure clinic at the Royal Hallamshire Hospital (Sheffield, UK) consented to participate in an observational study. As per routine practice, all patients were asked in their invitation letter to bring along a witness of their attacks if possible. Patients were eligible for inclusion if they had been referred to the clinic because of seizure disorders of uncertain aetiology for an initial consultation with one of three consultant neurologists, none of whom they had previously met. Participants were excluded if they were not fluent in English, had learning disabilities, or had undergone major neurological surgical intervention. This information was gathered from the patients' medical records prior to their attendance at the clinic. If uncertainty remained, patients (and where applicable, their companions) were approached while they waited to be seen, informed about the study, and inclusion/exclusion criteria were discussed and checked.

Consecutive eligible patients (and where applicable their companions) were invited to take part, and if they agreed, provided their written consent to participate. Consent was obtained on the day of the clinical encounter, before patients saw one of the participating neurologists. Reasons for non-participation were not formally recorded, but the reason most frequently cited involved apprehension about being video-recorded. Participant age, gender, and accompaniment status (attending alone or with a companion) were recorded. If patients were accompanied, the patient's relationship to the companion was recorded.

Participating neurologists and patients (and where applicable, their companions) were aware that recordings would be used to explore features that might help with the differential diagnosis of attacks. However, they did not know that their discourse contributions would be quantified. Participating neurologists were instructed to use their usual consultation ('interview') method.

Consultant neurologists reviewed patients' medical records six months after the initial appointment and confirmed their diagnosis at this point (when diagnoses were typically based on the history from patients and companions (if available) and investigations such as electroencephalography (EEG), video-electroencephalography (video-EEG), electrocardiography (EKG), and magnetic resonance imaging (MRI)). Researchers were not present during the consultations, which were video-recorded using a stand-alone device.

The author (CR) was responsible for obtaining NHS ethical approval and data collection oversight, including assessing patients' eligibility to participate, obtaining participant (patient and companion) consent, recording socio-demographic details, and for obtaining patients' diagnoses from participating neurologists at six month follow-up.

2.2 Procedure

A third party produced detailed verbatim transcripts of all recordings. However, video and audio recordings were examined alongside transcripts for clarification and to ensure correct transcription.

Two interactions were subsequently removed from the analysis to ensure comparability, one concerning an accompanied patient with (expressive) aphasia and a second consultation during which two accompanying persons were present. 48 interactions, consisting of a doctor and patient, or a doctor, patient and one companion, remained for analysis.

Recordings were analysed to determine the length of the consultation (in minutes). In a study of older adult patients (and where applicable, their companions) that attended a specialist (geriatric) outpatient appointment, Beisecker (1989) found that the duration of accompanied and unaccompanied interactions was not significantly different. This led Beisecker (1989) to propose

that companions take time away from patients in accompanied interactions. Examination of the duration of accompanied and unaccompanied interactions was important in this study as it provided a foundation from which Beisecker's claim could be assessed. In addition, the results of previous studies that have examined differences in the duration of accompanied and unaccompanied interactions in other clinical settings have been decidedly disparate (Wolff and Roter, 2012; Beisecker, 1989; Greene et al, 1994; Wolff and Roter, 2011; Ishikawa et al, 2005a and Labrecque et al, 1991). Therefore, it was important to assess differences in the duration of these different types of encounters in an outpatient neurology (seizure clinic) setting. In addition, if more time were needed for initial appointments where patients are accompanied, this information might be important to health service providers.

The focus of the study was to examine differences between the discourse spaces of participants (particularly patients) in unaccompanied and accompanied interactions in this clinical setting. This study did not examine the consultations of just those patients that were subsequently diagnosed with PNES or epilepsy at six-month follow up. Excluding the two cases described above, the entirety of the dataset was examined. As described below, this was done for two main reasons.

Firstly, had only PNES and epilepsy patient consultations been examined the sample would have been considerably (35%) smaller, there would have been significant differences in the ratio of unaccompanied and accompanied patient consultations undertaken by the three doctors that participated in the study, and there would have been significant differences in the age-range and gender of participants with PNES or epilepsy in the unaccompanied and accompanied patient groups. In addition, two consultations in which the patients were diagnosed with a dual diagnosis of epilepsy and PNES, and six cases in which the diagnosis of epilepsy or PNES was uncertain would have been excluded.

Secondly, regardless of their subsequent diagnosis, it was considered that all the patients that participated in the study attended the specialist seizure clinic to discuss transient loss of consciousness (TLOC) and/or reduced consciousness events (that the referring neurologists had considered possible seizures of an uncertain aetiology).

Therefore, it was believed better to include the entirety of the sample and use the findings as proxy measures for seizure patients, than to exclude patients without (firm) diagnoses of epilepsy or PNES and be left with a smaller sample with a number of significant differences between the accompanied and unaccompanied patient groups.

For the same reasons, those consultations in which the companion had not witnessed a seizure (or other paroxysmal neurological) episode were included in the study sample. In those consultations, a member of the patient-party had explicitly stated that the companion had not witnessed an event. The number and proportion of companions that had witnessed an episode is detailed in the results. The implications of including consultations in which the companion had not witnessed an episode are discussed in the limitations section of this chapter.

In line with the practice of previous authors (Shields et al, 2005), word counts were obtained from the analysis of transcripts to determine the discourse space occupied by patients, companions and doctors. Each consultation was analysed and the total number of words spoken in the consultation, and the total number of words spoken by individual participants, were calculated using a Microsoft word count tool. In addition, the proportion of words spoken by participants (discourse space) was calculated for all interactions (expressed as the proportion of words spoken by a particular participant to the total number of words spoken by all participants in the interaction). When a companion was present the total number of words spoken and the collective discourse space of the patient and companion combined (patient-party) was calculated.

Finally, following the methods of Street and Gordon (2008), the proportion of companion contributions to patient-party talk was calculated. Based on these scores, companions were placed into one of three categories: 'advocates', 'partners' and 'passive'. As Street and Millay (2001) have pointed out, it is recognised that participation cannot simply be measured by applying proportional measures of 'talk' to participants' conversational contributions; participation needs to be conceptualised qualitatively in relation to the type of speech acts participants produce and the effect of these speech acts, and quantitatively with respect to the frequency of these behaviours. The labels used here to categorize companion contributions to patient-party talk (passive,

partner and advocate) were not intended to describe nor assess companion participation in the encounters (i.e. as defined by Street and Millay, 2001). The measures did, however, provide a useful system from which the verbal contributions of companions to patient-party talk could be quantitatively assessed.

2.3 Statistical methods

Given the small sample size and opportunistic sampling method used in the study, non-parametric statistical methods were used to analyse data.

Clinical and demographic differences between the unaccompanied and accompanied patient groups were examined using the Fisher exact test. The Freeman-Halton extension of the Fisher exact test was applied to contingency tables exceeding the two row by two column format (Freeman-Halton, 1951).

In line with the methods offered by Street and Gordon (2008), the proportion of companion contributions to patient-party talk was analysed. Companions were categorised as 'passive' when they contributed less than 40% to patient-party talk, 'partners' when they contributed 40% to 60% to patient-party talk, and 'advocates' when they contributed more than 60% to patient-party talk. Descriptive results of this analysis are presented.

The Mann-Whitney U test was applied to determine the significance of differences in interview length, total number of words, total participant number of words spoken and discourse spaces occupied by participants in accompanied and unaccompanied interactions. The Wilcoxon signed-rank test was applied to determine the significance of differences between participant discourse spaces in related samples - that is, differences between patient and doctor discourse spaces in unaccompanied interactions, and differences between patient, doctor and companion discourse spaces in accompanied interactions.

Finally, after establishing there were no repeated values in the data, Spearman's rank correlation coefficient was calculated to determine the strength, direction and significance of correlation between participant discourse spaces in unaccompanied and accompanied interactions. Spearman's rho was

defined as very weak (r 0–0.19), weak (r 0.20–0.39), moderate (r 0.40–0.59), strong (r 0.60–0.79), or very strong (r 0.80–1.00).

Two-sided p-values of <0.05 were considered statistically significant throughout.

3. Results

Of the 48 interactions analysed, 18 (37.5%) patients attended alone and 30 (62.5%) were accompanied. There were no significant differences in the ratio of accompanied and unaccompanied patients seen by the three doctors that participated in the study (p0.57). 20 (66.7%) of the accompanied patients had brought along a spouse or partner, six (20.0%) were accompanied by a parent and four (13.3%) were accompanied by other companions (one sibling, two friends, and one carer). Of the 30 accompanying persons, 23 (76.7%) had witnessed a patient's blackouts or other reduced consciousness event.

As detailed below in table 8, no significant differences were found between unaccompanied and accompanied groups in relation to age distribution, gender and diagnosis of patients.

Table 8: Clinical and demographic features of accompanied and unaccompanied consultations

		Unaccompanied patients (n=18)	Accompanied patients (n=30)	Significance (Fisher Exact test)
Age	20 to 35 years	4	11	p0.830
	36 to 50 years	6	9	
	51 to 65 years	6	7	
	65+ years	1	3	
Gender	Male	11	16	p0.765
	Female	7	14	
Diagnosis	Epilepsy	6	11	p0.729
	Psychogenic non-epileptic seizures	4	10	
	Syncope	3	3	
	Other, unknown or dual diagnosis*	5	6	

*Other, unknown or dual diagnosis included, propriospinal myoclonus, sleep paralysis and episodic vertigo, two cases of dual diagnosis (epilepsy and PNES) and six cases in which the diagnosis was uncertain.

As detailed in table 9 below, accompanied consultations were found to be marginally longer than unaccompanied consultations, however, this difference was not statistically significant. Similarly, no significant difference in the total number of words spoken was found between unaccompanied and accompanied consultations.

Table 9: Differences in the length (minutes) and total number of words spoken in unaccompanied and accompanied consultations

	Unaccompanied (n=18)	Accompanied (n=30)	Significance (MWU)
Median length (and range)	22.9 (9.3 to 41.1)	23.3 (8.5 to 58.1)	p0.589
Median words spoken (and range)	4133 (1420 to 6936)	3713 (1695 to 11581)	p0.749

Patients spoke significantly fewer words (median difference 830.5, $p < 0.01$) and occupied proportionally less discourse space (median difference 29%, $p < 0.0001$) in accompanied interactions. Notably, results suggest that the median discourse space occupied by doctors was greater in the accompanied interactions (53%) compared to the unaccompanied interactions (43%). Correspondingly, the proportion of the patient-party discourse space decreased in accompanied interactions (by nearly 10%). However, as detailed in table 10, these differences did not achieve significance in the dataset.

Table 10: Differences in the number of words spoken and discourse spaces of participants in unaccompanied and accompanied interactions

Median number, proportion* (and range) of words	Unaccompanied interactions (n=18)	Accompanied interactions (n=30)	Significance (MWU)
Patients	2137.5 (848 to 4526)	1307 (353 to 3745)	p0.009
	56.9% (31% to 72.6%)	28.3% (11.6% to 62.9%)	p<0.0001
Patient-party [^]	2137.5 (848 to 4526)	2276 (458 to 4989)	p0.905
	56.9% (31% to 72.6%)	47.4% (26.4% to 74.3%)	p0.063
Doctors	1985.5 (572 to 3073)	2045 (579 to 6592)	p0.246
	43.12% (27.4% to 69%)	52.6% (25.7% to 73.6%)	p0.063

*Mean proportion of words by the participant to the total number of words produced by all participants in the consultation.

[^]Patient-party is defined as patient contributions in unaccompanied (dyadic) interactions and the combined contributions of patients and companions in accompanied (triadic) interactions.

In accompanied interactions, companions were observed to contribute a median of 35% (range 1% to 76%) to patient-party talk and patients 65% (range 24% to 99%). In line with Street and Gordon's (2008) methods, companions were classified as 'passive', 'partners', or 'advocates'. 63% of companions participating in the interactions were identified as 'passive' (contributing less than 40% to patient-party talk), 17% were identified as 'partners' (contributing 40% to 60% to patient-party talk) and 20% were classified as 'advocates' (contributing more than 60% to patient-party talk). The median contribution of 'passive' companions to patient-party talk was 18% (range 1% to 40%), 'partner' companions 41% (range 41% to 60%) and 'advocate' companions 69% (range 63% to 76%).

As detailed in table 11 below, analysis of individual participant discourse spaces suggested that doctors occupied significantly more discourse space (median 53%) than patients ($p < 0.0001$) or companions ($p < 0.0001$) in the accompanied interactions. However, patients occupied significantly more discourse space (median 28%) than companions (median 16%) ($p < 0.003$).

No differences were identified between the correlation of discourse spaces of patients and doctors in unaccompanied interactions ($r = -1$, $p < 0.0001$) and between patient-parties and doctors in accompanied interactions ($r = -1$, $p < 0.0001$).

In accompanied interactions, patient-companion ($r = -0.64$, $p < 0.001$) and doctor-patient ($r = -0.43$, $p < 0.017$) discourse spaces were significantly correlated. Changes in the individual discourse spaces of companions and (to a lesser extent) doctors were significantly associated with changes in the discourse spaces of patients (and vice-versa). No significant association between the discourse spaces of companions and doctors was observed in the interactions ($r = -0.31$, $p < 0.100$).

Table 11: Differences between and correlation of the discourse spaces of participants in unaccompanied and accompanied interactions.

Participants	Median proportion* (and range) of words	Participants	Median proportion* (and range) of words	Significance ⁺	Correlation coefficient [^]
Unaccompanied interactions (n=18)					
Patients	56.9% (31% to 72.6%)	Doctors	43.12% (27.4% to 69%)	p0.162	$r_s = -1$ (p<0.0001)
Accompanied interactions (n=30)					
'Patient parties' ^{>}	47.4% (26.4% to 74.3%)	Doctors	52.6% (25.7% to 73.6%)	p0.342	$r_s = -1$ (p<0.0001)
Patients	28.3% (11.6% to 62.9%)	Companions	16.0% (0.3% to 46.8%)	p0.003	$r_s = -0.64$ (p0.001)
Companions	16.0% (0.3% to 46.8%)	Doctors	52.6% (25.7% to 73.6%)	p<0.0001	$r_s = -0.31$ (p0.100)
Doctors	52.6% (25.7% to 73.6%)	Patients	28.3% (11.6% to 62.9%)	p0.0001	$r_s = -0.43$ (p0.017)

*Mean proportion of words by the participant to the total number of words produced by all participants in the consultation.

⁺ Wilcoxon signed-rank test (p)

[^] Spearman's rank correlation coefficient (Spearman's rho) (r_s) and significance (p)

[>] 'Patient parties' are defined as the combined contributions of patients and companions.

4. Discussion

Reports from other clinical settings demonstrate that the proportion of adults accompanied to visits can vary considerably; between up to 75% of patients in oncology to 16% in primary care (Beisecker and Moore, 1994 and Schilling et al, 2002). In the sample described here, nearly two thirds of the new patients that attended the seizure clinic and consented to participate in this study complied with the request in the invitation letter to bring along a companion when attending for their first appointment. Over three quarters of these accompanying persons had witnessed the patient's blackouts or other reduced consciousness events. Most commonly, these patients brought along their partner or spouse. Studies from other clinical settings have identified that adult patients are most often accompanied by their spouse or partner (Clayman et al, 2005; Ishikawa et al, 2005a; Barone, Yoels and Clair, 1999; Prohaska and Glasser, 1996; Hasselkus, 1992; Glasser, Prohaska and Gravidal, 2001 and Tsai, 2000).

The findings indicate that patients with epilepsy or PNES are perhaps more likely to be accompanied in the clinic than those with syncope (two thirds, versus one half), but the group sizes were too small for meaningful statistical analyses. The three most common diagnoses in the seizure clinic (epilepsy,

PNES, syncope) did not appear to be linked to the likelihood of patients attending with a companion who had witnessed an event.

A number of studies have explored differences in the duration of accompanied and unaccompanied interactions in other medical settings. However, despite studies reporting that accompanied visits are marginally longer, some report a non-significant difference (Wolff and Roter, 2012; Beisecker, 1989; Greene et al, 1994) and others a significant difference (Wolff and Roter, 2011; Ishikawa et al, 2005a and Labrecque et al, 1991). No significant differences were observed in this study between the duration or total word count of accompanied and unaccompanied interactions, suggesting, as Beisecker (1989) proposed, that time is taken away from the patient when a companion is present. Correspondingly, our data confirms that the presence of a companion significantly reduces (more than halves) the discourse space available to patients.

However, whereas Beisecker (1989) assumed patient discourse space would be lost to companions, the discourse space lost by patients in the data was not taken up by companions alone. As found in other clinical settings (Wolff and Roter, 2011), in the seizure clinic data the majority of the discourse space in accompanied and unaccompanied interactions was occupied by doctors. Although the difference did not achieve statistical significance in the (modestly sized) dataset ($p=0.06$), the median discourse space of doctors was observed to increase by nearly 10% in the accompanied interactions. One possible explanation for this is that doctors have to 'do more work' in these accompanied encounters. Authors have reported a marginal increase in the discourse space occupied by doctors in other clinical settings when a companion is present (Shields et al, 2005). However, the majority of studies that have explored participant discourse space report a marginal decrease in the verbal activities of doctors when a companion is present (Wolff and Roter, 2012; Ishikawa et al, 2005a and Street and Gordon, 2008). Nevertheless, previous studies do show that doctors engage in significantly less questioning and more information giving (explaining) when third parties are present (Wolff and Roter, 2012). In addition, doctors have been observed to take significantly longer speaker turns in encounters where a third person is present (Shield's et al, 2005).

There was no significant difference between the discourse space occupied by doctors and that occupied by patient-parties (i.e. the combined contributions of patients and companions) or patients alone in the dataset. In accompanied interactions, patients were observed to occupy significantly more discourse space than companions (median difference 12%).

Differences in participant discourse spaces observed in this study broadly reflect those found in other clinical settings (Wolff and Roter, 2012; Ishikawa et al, 2005a; Shields et al, 2005 and Street and Gordon, 2008), and the pooled results of a recent meta-analysis of accompanied medical interactions with adult patients (Wolff and Roter, 2011).

This is the first known study to examine correlations in participant discourse spaces of accompanied interactions. In the data, the discourse space occupied by the doctor and the patient, or doctor and patient-party, are (obviously) perfectly (inversely) correlated (the more space is occupied by the doctor, the less is available for the patient or patient-party, and vice versa). Investigation of participant discourse space in the accompanied data showed that the discourse spaces of doctors and companions were not (significantly) correlated. That is, the discourse spaces occupied by companions were not significantly associated with changes in the discourse space of doctors (and vice-versa). Attempts by companions to form alliances (coalitions) with doctors have been observed in other clinical settings. However, authors have reported that doctors usually deflect these attempts, by redirecting questions to patients or by changing topic (Coe and Prendergast, 1985). This may help to explain why a weak non-significant correlation between the discourse spaces of doctors and companions was observed in the seizure clinic data; and why doctors appear to ‘work harder’ (be more verbally active) in these encounters.

Results suggest that the discourse space of patients is weakly (but significantly) associated with the discourse space of doctors in these encounters ($r_s=0.43$, $p0.017$). From the doctor’s perspective, these results appear to substantiate the patient-doctor relationship as the primary alliance in these encounters. In addition, accompanied patients were found to occupy significantly more discourse space than companions in the data, suggesting (using verbal activity as a proxy measure) that patients are usually the primary providers of information in these encounters. Similarly, using Street and Gordon’s (2008)

classification system, findings suggest that nearly two-thirds of the accompanying persons in the seizure clinic encounters were 'passive', contributing less than 40% to patient-party talk.

However, one-fifth of companions in the sample were observed to be 'advocates', contributing more than 60% to patient-party talk, and markedly more verbally active than the patients they accompanied. In addition, findings from the analysis suggest that the discourse space of patients was moderately to strongly associated with changes in the discourse spaces of companions ($r_s = 0.64$) and that this correlation was significant ($p < 0.001$).

Structurally, these results imply that in accompanied interactions patient discourse spaces are primarily determined by the contributions of companions, and to a lesser extent, doctors. Given that there was no significant difference in the median lengths of unaccompanied and accompanied interactions, the presence of a companion therefore reduces the space available for the patient's rather than the doctor's contribution to the interaction.

These findings suggest that the presence of an accompanying person could reduce opportunities for doctors to observe the differential interactional, linguistic and topical features of seizure patient talk. This appears likely given that many of the differential markers identified are within the privileged epistemic domain (self-knowledge) of patients (Heritage, 2012), which is evident in patients' negation of periods of reduced self-control and consciousness, subjective seizure symptom descriptions, and metaphorical conceptualizations of seizure episodes (Guelich and Schoendienst, 1999; Schoendienst, 2001; Furchner, 2002; Surman, 2005, cited in Schwabe et al, 2008; Schwabe, Howell and Reuber, 2007; Plug, Sharrack and Reuber, 2009a, 2009b, 2009c and Reuber et al, 2009).

The interactive influence of the companion may also impact other interactional, linguistic and topical features of seizure patient talk, such as the extent that patients initiate and are able to focus on seizure descriptions, and the formulation work (e.g. hesitations, pauses, restarts) used by patients when describing attacks.

Patients in other clinical settings have been observed to be less assertive and expressive (Greene et al, 1994) when a companion is present. In addition, companions have been reported to volunteer information (Beisecker, 1989) and answer on behalf of the patient (Greene et al, 1994), and proportionally more of their [companion's] talk has been defined as 'active', that is, asking questions, expressing concerns, and stating an opinion or preference (Greene et al, 1994 and Street and Gordon, 2008). These behaviours may influence seizure patient accounts.

The presence of companions in this setting may, therefore, significantly reduce the diagnostic yield and/or the differential potential of the interactional, linguistic and topical patient markers previously observed in one-to-one doctor-patient interactions.

However, in these encounters companions may provide essential additional diagnostic information. Companion eyewitness accounts of seizures and descriptions of factual seizure items can be crucial for clear diagnosis (Chowdhury, Nashef and Elwes, 2008). In other clinical settings, companions have been observed to assist in other information giving, and to help patients recall and construct medical histories (Wolff and Roter, 2011). In addition, a community-based study of accompanied seizure (epilepsy) patients suggested that companions helped to track patient symptoms over time (Gilliam et al, 2009). Companions may also help the patient to understand the doctor's explanations in a seizure clinic clinical setting. Companions in other clinical settings have been found to ask significantly more questions than patients (Eggly et al, 2006 and Ishikawa et al, 2005a) and be particularly active in diagnostic testing discussions (Eggly et al, 2006), traits that may be particularly beneficial for patients during diagnosis, treatment and seizure management discussions.

5. Limitations

This study has a number of limitations. A relatively small sample of patients is described. In addition, only basic demographic participant information was collected. For example, participants' level of education, their sociocultural and ethnic backgrounds and their linguistic abilities were not recorded. These factors may have had effects on their contributions to their first appointment in the seizure clinic. Furthermore, the non-consent rate of patients (and where applicable, their companions) that declined to participate in the study was not recorded. There may have been significant differences between participants that chose to participate in this study and those that did not. This means that it is impossible to estimate how representative this data may be.

Moreover, the findings are based on the observation of communication practices of only three doctors working in one epilepsy clinic. Although the participating neurologists were instructed to follow their usual communication practice it may be that their approach was somehow shaped by their shared working environment, limiting the generalisability of the findings presented here. In addition, participants that chose to participate in this study may have varied their behaviour as a consequence of observation. As Cahill and Papageorgiou (2007a) have commented, participants that are observed may respond by being unusually quiet or making an unusual effort to talk.

In addition, this study included patients other than those subsequently diagnosed with epilepsy or PNES at six month follow up. Although no significant differences between the unaccompanied and accompanied groups were observed in relation to patients diagnoses, it must be remembered that the findings presented here relate to a group of patients seen in a specialist seizure clinic, and not seizure patients per se (i.e. those diagnosed with epilepsy or with PNES). As such, findings can only be used as indicative or proxy measures for consultations with 'seizure' patients. Similarly, approximately one-quarter of the companions in this study had not witnessed a patient's episode. In accompanied interactions, companions that have witnessed a patient's attack may contribute more talk than those that have not. Had only companions that had witnessed a seizure episode been included in this study, the influence of companion discourse space on that of patients (and possibly doctors) may have

been greater than that seen here. This possibility is explored in the next chapter of this thesis.

It is also important to note that, in comparison to most other studies in this area, the data analysed here consisted of initial consultations that Labrecque et al (1991) have suggested constitute unique interactions. Moreover, the study took place in a specialist (seizure-clinic) setting. This may mean that the results observed here are not found in other clinical environments.

Finally, this is the first known study to explore associations between participant discourse spaces in accompanied interactions. The lack of comparative data means that it is not clear whether the finding that accompanying persons take time from the patient and not the doctor is replicated in other clinical settings. In addition, the quantitative approach taken does not reveal why this was the case in this study, or why doctors appeared to talk more and had to 'work harder' in the accompanied interactions described here.

6. Conclusion

Despite these limitations, this study provides some important insights. The study is the only known research from the UK to explore differences in the duration of unaccompanied and accompanied medical consultations, one of only a handful internationally to investigate differences in participants' discourse spaces, and the only known study to explore these features in a neurology out-patient setting.

The results suggest that the important diagnostic contributions companions can make in first encounters between neurologists and patients with seizures may not come without a cost. The presence of companions in these encounters may reduce the discourse space patients need to describe their experiences and demonstrate diagnostically useful interactional, linguistic and topical features.

In order to optimise the diagnostic potential of information doctors can obtain from patients and from seizure witnesses it may be advisable to interview patients on their own first, before asking the accompanying person to join the discussion. Authors exploring interactions with adolescents and their parents have previously identified this approach as preferable (van Staa, 2011). Doctors

unwilling to do this may be able to restrict accompanying persons' contributions (at least in the early part of the encounter) by formulating a consultation structure, and stating that they would like to talk to patients initially and hear from the accompanying person at a later stage in the encounter.

However, more work is needed to determine if this is a suitable solution. In addition to the (obvious) benefits of a seizure witness account, it may be that there are conversational diagnostic pointers in the contributions of companions to first doctor-patient encounters in the seizure clinic, or that the doctor's observation of the interaction between patients and companions could yield data of differential diagnostic significance (such as the head-turning sign described in the dementia clinic) (Bouchard and Rossor, 1996). No previous studies have looked at these aspects of communication in the seizure clinic. To date all studies examining patients' and witnesses' accounts of seizures have focussed on factual content (Mannan and Wieshmann, 2003 and Reuber et al, 2011).

In the next chapter this thesis (chapter six), the discourse spaces of participants in consultations with seizure (epilepsy or PNES) patients accompanied by a seizure-witness spouse or partner were explored. In addition, qualitative (predominantly microanalytic) methods were used to examine the interactive behaviours of seizure witness companions in these interactions, potential conversational diagnostic pointers between patients and companions, and the effects of companionship on an important differential feature of seizure patient talk - subjective seizure symptoms.

**Chapter six: The effects of spouse or partner seizure-witness companions
in seizure-clinic encounters.**

1. Introduction

This study examined outpatient encounters between neurologists and seizure patients who were accompanied by a spouse or partner who had witnessed a seizure episode.

Descriptions from third party witnesses who have seen patients' episodes can play a significant role in making accurate diagnoses (Chowdhury, Nashef and Elwes, 2008; Leach et al, 2005; and Smith, Defalla and Chadwick, 1999). Consequently, patients are encouraged to bring seizure witnesses along to neurology (seizure clinic) appointments as a matter of routine in the letter they receive inviting them to their appointment. However, despite the important roles companions often play in seizure-clinic encounters, no previous studies have focused specifically on their contribution to the interaction between patients and health professionals. This exploratory study aimed to expand what is known about the effects of companions in these interactions.

Several studies discussed previously have demonstrated the diagnostic potential of sociolinguistic micro-analytic observations which can be made in the talk of seizure patients when these patients talk to a neurologist on their own (Guelich and Schoendienst, 1999; Schoendienst, 2001; Furchner, 2002; Surmann, 2005; Schwabe, Howell and Reuber, 2007; Schwabe et al, 2008; Plug and Reuber, 2009, 2012; Plug, Sharrack and Reuber, 2009a, 2009b; Reuber et al, 2009). The analysis of contributions of third parties to the interaction between doctor and patient (more specifically, the interaction between patient and accompanying person or between accompanying person and doctor) could yield additional diagnostic pointers. However, as was observed in chapter five, the presence of companions in these encounters appears to reduce the discourse space available to patients. Moreover, companions may have the capacity to influence patients' descriptions of their attacks. This may mean that the differential interactional, linguistic and topical features of seizure patient talk identified in one-to-one doctor-seizure patient interactions are in fact reduced, influenced or obscured by the presence of a companion.

1.1 Aims and objectives

The first aim of this study was to examine the extent to which the PNES and epilepsy patient consultations included in the sample selected for analysis were comparable. To establish if this was the case, objectives included: examining clinical and demographic differences between the PNES and epilepsy patient samples, establishing if the epilepsy and PNES patient consultations were comparable at a quantitative (discourse space) level, and assessing the topical phases of these consultations, focusing particularly on history-taking phases.

A further aim of the analysis was to assess the extent to which the discourse spaces of seizure patients were influenced by the presence of their seizure witness companion. To do this, correlations between participant discourse spaces and companion contributions to patient-party talk were examined.

Following this, the analysis aimed to explore whether there were conversational pointers of differential diagnostic significance in the interaction between participants in the encounters. The main objective of this analysis was to explore how companions became involved in the interactions to 'gain the floor' and describe what they had witnessed. This analysis included examining the resistance displayed by patients with epilepsy and patients with PNES to describe their seizure experiences, and the reliance placed on companions to describe what they had seen.

The final aim of the study was to explore whether, and in what ways, companion contributions had the capacity to influence, obscure or limit the diagnostically helpful conversational contributions of patients. To do this, a recognised differential marker of seizure patient talk was assessed: subjective seizure symptoms, i.e. what the patient had thought or felt before, during or after a seizure episode.

2. Methods

2.1 Data collection

Using the methods described in the previous chapter (chapter five), 50 patients who attended an initial neurology outpatient appointment at a specialist seizure-clinic and who were experiencing attacks of uncertain aetiology (and where applicable, their companions) gave informed consent to participate in an observational study. The study involved observation of routine clinical practice. Consultations were video-recorded and detailed verbatim transcripts of all recordings were produced.

2.2 Sample selection

Of the 50 patients that agreed to participate in the study, 23 patients accompanied by a companion were subsequently diagnosed with either epilepsy or PNES. To ensure comparability, two interactions were excluded at this stage, one concerning an accompanied patient with (expressive) aphasia (attending with their spouse) and a second consultation with two accompanying persons present (the patient's spouse and son).

Five of the companions in the remaining 21 consultations had not witnessed a seizure episode (two from the PNES patient group and three from the epilepsy patient group). In these interactions, a member of the patient-party explicitly stated that the companion had not witnessed a seizure event. The verbal activity of these companions (n=5) was very low. The median discourse space of 'non-witness' epilepsy patient companions (n=3) was 2% (range 1% to 11%) and the median discourse space of 'non-witness' PNES patient companions (n=2) was 6% (range 5% to 7%).

Of the 16 patients who were diagnosed with epilepsy or PNES and were accompanied by one companion who had witnessed a seizure episode, by far the largest group (n=13, 81%) were those accompanied by their spouse or partner. These thirteen consultations formed the sample studied in this analysis.

2.3 Statistical methods

Given the small sample size and the opportunistic sampling method used to collect data, non-parametric statistical methods were used.

Clinical and demographic differences between PNES and epilepsy patient groups (differences between patient and companion gender, patient age range, patient diagnoses and the ratio of PNES and epilepsy patient consultations undertaken by the two doctors participating in the interactions) were examined using Fisher Exact test. The Freeman-Halton extension of the Fisher Exact test was applied to contingency tables exceeding the two row by two column format (Freeman-Halton, 1951). Differences between the lengths (in minutes) of PNES and epilepsy patient consultations were analysed using the Mann-Whitney U test.

In line with the practice of previous authors (Shields et al, 2005), the total number of words spoken in the consultations, and the total number of words spoken by individual participants (doctors, patients and companions) were calculated using a Microsoft word count tool. The discourse spaces of participants (the number of words spoken by a particular participant as a proportion of the total number of words spoken by all participants in the interaction) were calculated. Please see chapter five for further details of these methods.

Differences between the discourse spaces of participants in PNES and epilepsy patient consultations were assessed. The Mann-Whitney U test was applied to determine the significance of differences between the total number of words spoken, total participant number of words spoken, and discourse spaces occupied by participants in PNES and epilepsy patient interactions. Due to the low number of patients in each diagnostic group, correlation of participant discourse spaces between epilepsy patient encounters and PNES patient encounters was not possible.

To assess the extent to which the discourse spaces of seizure patients were influenced by the presence of their seizure witness companion, differences between the discourse spaces of participants and their correlation were examined across the entirety of the sample (all 13 consultations). The Wilcoxon

signed-rank test was used to determine the significance of differences between participant (patient, companion and doctor) discourse spaces. After establishing there were no repeated values in the data, Spearman's rank correlation coefficient was calculated to determine the strength, direction and significance of correlation between participant discourse spaces. Spearman's rho was defined as very weak ($r = 0-0.19$), weak ($r = 0.20-0.39$), moderate ($r = 0.40-0.59$), strong ($r = 0.60-0.79$), or very strong ($r = 0.80-1.00$).

Following an established definition (Street and Gordon, 2008), companions in the data were defined as 'passive' when they contributed less than 40% to patient-party talk (the combined contributions of the patient and companion), 'partners' when they contributed 40% to 60% to patient-party talk, and 'advocates' when they contributed more than 60% to patient-party talk. As previously discussed in chapter five, the labels used to categorize companion contributions to patient-party talk ('passive', 'partner' and 'advocate') were not intended to describe nor assess companion participation (for example, as defined by Street and Millay, 2001). The measures did, however, provide a useful pre-determined system from which the verbal contributions of companions to patient-party talk could be quantitatively assessed.

Two-sided p-values of <0.05 were considered statistically significant throughout.

2.4 Qualitative methods

2.4.1 Descriptive research methods

Topical consultation phases were identified using descriptive research methods. The analysis began by repeatedly viewing consultation recordings and transcripts in order to become immersed in the data, which is a recognised first-step in qualitative analysis (Marshall and Rossman, 1999). During this process, the manifest content (Graneheim and Lundman, 2004) of the consultations was examined and data were labelled as belonging to different consultation phases according to "*what gets talked about*" (Roberts and Sarangi, 2005, p633). Sandelowski (2000) has described researchers that conduct qualitative descriptive studies as seeking to convey the topical content and sequence of events of data; they "*stay close to their data and to the surface of words and events*" (p334). The latent content, the underlying meanings of the text

(Graneheim and Lundman, 2004), were not examined in this stage of analysis. The exercise did not extend beyond a topical overview of the data, a description of the typical sequence (organisation) of the topical history-taking phases identified, and the commonality of these across the consultations selected for analysis.

Another important purpose of the exercise was data management and organisation. The data were categorised and reduced into 'manageable chunks' (Marshall and Rossman, 1999), a necessary procedure in most qualitative analyses (Miles and Huberman, 1994). This process was initially driven by previous research findings from the literature, and a directed (deductive) approach (Hsieh and Shannon, 2005) was taken in the first instance.

Transcripts were sub-divided into five broad consultation phases. These were based on those identified in previous neurology (seizure clinic) encounters: (1) history-taking, (2) discussion of examination and test results, (3) diagnosis, (4) explanation of likely aetiology, and (5) treatment recommendations (Monzoni et al, 2011). In the study described here, discussions of examination and test results were incorporated into the category 'diagnosis', and an additional category, 'introductions', was added.

The main focus was on the history-taking phases of consultations. As described, patient descriptions of attacks, particularly discussions of periods of reduced consciousness and unconsciousness, have been central to previous research examining the diagnostically differential interactive, linguistic and topical markers of seizure patient talk (Guelich and Schoendienst, 1999; Schoendienst, 2001; Furchner, 2002; Surmann, 2005; Schwabe, Howell and Reuber, 2007; Schwabe et al, 2008; and Plug, Sharrack and Reuber, 2009a, 2009b and Reuber et al, 2009).

Data identified as within history-taking consultation phases were organised into further subcategories according to topical content. In practice, all topical categorisation activities in the study involved colour-coding transcripts using Microsoft Word (where a range of colours are available, and markers can be easily changed with each subsequent pass of the data, if necessary). Many qualitative researchers use this, or a similar system, when organising and categorising data for analysis (e.g. Babis, 2002). Using this system, data that

had previously been classified as belonging to the 'history-taking' phase of consultations were repeatedly examined and labelled according to topical content. After topical history-taking content had been identified, the entirety of the data were re-examined to ensure that no applicable data had been incorrectly categorised or missed. It is important to note that during this process data were not extracted from the transcripts, but remained 'in context'. This was an important consideration for the qualitative analyses described below.

Figure 4, in the results section of this chapter details the topical content of the different history-taking phases identified in the data. An overview of the typical structural organisation of these history-taking phases (in what order they were typically discussed in consultations) and the topical commonality of these phases across consultations selected for analysis is also presented. Of the topical history-taking phases identified in the data, four phases were identified that included topical content that related to descriptions of patients' attacks and periods of reduced consciousness or unconsciousness. These history-taking phases became the focus of later qualitative analyses. The analytical approach taken to these analyses is described below.

2.4.2 Qualitative analyses: a hybrid approach

A hybrid analytical approach that combined elements of Discourse Analysis (DA) and Conversation Analysis (CA) was used to examine potential diagnostic conversational pointers in the interaction between patients and companions, and the potential influence of companion descriptions on those of patients.

Discourse analysis (DA) is a broad term used to describe various analytical approaches; in its modern form(s), it is often cited as originating with Noam Chomsky's teacher and mentor, Zellig Harris, in 1952 (Paltridge, 2006). Throughout the 1960s various semiotic and linguistic methods were applied to the study of discourse, and by the early 1970s, systematic discourse analysis had emerged as an independent entity across a variety of disciplines (van Dijk, 1985). The influence of these different disciplines has led to a myriad of discourse analysis methods being developed. Some of these, such as Conversation Analysis (CA) arise from or are bound to a distinct theoretical or epistemological position (Wooffitt, 2005). Although CA can be seen to be encapsulated under the banner of DA, there are distinct differences between

DA and CA in terms of focus, the methods used, and the theoretical and epidemiological stances taken.

CA was developed by Harvey Sacks and his colleagues, Emanuel Schegloff and Gail Jefferson in the 1960s, and had some affinities with Harold Garfinkel's ethnomethodology (e.g., 1967) and Erving Goffman's work on social interaction (e.g., 1955, 1959, 1961, 1967) (see Heritage, 1984).

CA is the systematic analysis of the sequence and organisation (verbal and non-verbal) of 'naturally occurring' interactions (Drew and Heritage, 2006). A central tenet of CA is that interaction is orderly. Sacks, Schegloff and Jefferson (1974) described the fundamental ways in which speakers manage conversation, and observed that, "*overwhelmingly, one party talks at a time, though speakers change, and though the size of turns and ordering of turns vary; that transitions are finely coordinated; [and] that techniques are used for allocating turns*" (p699). From a CA perspective, coherence and understanding are made possible in conversation by a "*common set of methods or procedures*" (Heritage, 1984, p241) employed by participants when they interact. CA researchers analyse these 'methods or procedures', and examine the organisation of turn-taking, sequence (action) and repair in interaction (Ten Have, 2004).

As Heritage has explained, CA studies, "*describe how people take turns at talk in ordinary conversation and negotiate overlaps and interruptions; how various kinds of basic action sequences are organised and different options are activated inside those sequences; how various kinds of failures in interaction – for example, of hearing and understanding – are dealt with; how conversations are opened and closed; how gaze and body posture are related to talk; how laughter is organised; how grammatical form and discourse particles are related to turn taking and other interactional issues*" (Heritage, 2004, p222).

A focus on action is embodied within the epistemological and methodological positions taken by conversation analysts. As Drew and Heritage (2006) have reported, "*CA methodology is action-focused. The goal is to identify the patterns, practices or devices which underlie meaning and action*" (Drew and Heritage, 2006, p9). Schegloff, Jefferson and Sacks (1973) described CA as a, "*naturalistic observational discipline dealing with the details of social action*

rigorously, empirically and formally" (p289). Grounded in an ethnomethodological framework, conversation analysts consider conversational interaction to be the "*sociological bedrock*", and "*a form of social organisation through which the work of the constitutive institutions of societies gets done*" (Schegloff, 2001, p231). That is, social action and organisation derive from conversation and the ways in which people interact with one another.

Consequently, CA research is data-driven, and the application of external concepts or categories and preconceived hypothesis testing are avoided in favour of what is observable in the data. Conversation analysts do take account of the contexts of interactions, but only in so far as participants in the data orientate to these and they are "*demonstrable in their actions, in what they actually say and do*" (Psathas, 1995, p.95). As Drew and Heritage (2006) have explained, "*CA takes the position that the 'context' of an interaction cannot be exhaustively defined by the analyst a priori; rather, participants display their sense of relevant context (mutual knowledge, including what each knows about the other; the setting; relevant biographical information; their relevant identities or relationship, etc.) in the particular ways in which they design their talk*" (p6). Similarly, there are strict criteria governing the kinds of interpretations that can be made from the data in CA. As Drew et al (2001) have noted, "*CA's method is an observational science: it does not require (subjective) interpretations to be made of what people mean, but instead is based on directly observable properties of data*" (p67).

The methods used in this study utilised CA's microanalytic focus on conversational activities and the sequential analysis of turns-at-talk, but the analysis was undertaken within a broader DA framework - one of the main reasons being that people with PNES and epilepsy have distinct communication profiles that can contribute to the differential diagnosis of their seizure condition (as described in chapter two). This premise goes against the grain of the underlying assumptions of CA. As Drew et al (2001) have reported, conversation analysts "*look for what are recurrent and systematic patterns, which do not arise from or depend upon participants' idiosyncratic styles, particular personalities or other individual or psychological dispositions*" (Drew et al, 2001, p60). In contrast, DA recognises that social and cultural variables (for example, class, race, ethnicity, gender, nationality) influence speech production and the ways in which people interact with one another

(Hammersley, 2003). In DA, the social and cultural identities of participants are used to explain how and why they interact with one another in the ways they do (Jørgensen and Phillips, 2002). Unlike CA, DA analysis is not strictly confined to what is observable in the data, and predetermined categories, concepts and hypotheses can be brought to bear on the data.

The other main reason that a DA framework was adopted was that analyses included targets of inference that were beyond (larger than) those traditionally examined by conversation analysts. From a linguistic perspective, DA approaches to interaction are said to analyse discourse 'beyond the sentence' or 'clause' (Gee, 2001). However, as Wooffitt (2005) has pointed out, "*this does not mean that discourse analysts are uninterested in specific conversational activities or their sequential contexts; rather, their interest is not restricted to the level of that action*" (p54).

It is not unusual to take a hybrid approach to the study of discourse (Ainsworth-Vaughn, 2001). Some communication analysts advocate the use of mixed approaches to qualitative analysis. Jørgensen and Phillips (2002) have recommended that, "*different approaches are combined in an attempt to make use of several of the approaches' strong points in analysis*" (p148). Similarly, many now well-recognised approaches to discourse are combinations of analytical approaches. "*Discourses and discourse topics 'spread' to different fields and discourses. They cross between fields, overlap, refer to each other, or are in some other way sociofunctionally linked with each other*" (Heller 2001, p383). To give an example, Discursive Psychology (DP) was developed by Potter and Edwards in the 1990s, originating from Potter and Wetherell's (1987) work on discourse and social psychology. DP draws upon classic rhetorical thinking, ethnomethodology, and CA (Potter and Edwards, 2001). Using CA methods to analyse data, DP analysts seek to understand how psychological phenomena are inter-subjectively created and understood in 'naturally occurring' interactions (Wiggins and Potter, 2008).

As previously mentioned in chapter two, it is also important to note that previous studies that have explored the diagnostically differential features of seizure patient talk have not used one distinct (formal) method (such as CA) to analyse data. Plug, Sharrack and Reuber (2009a) have described the studies undertaken by the '*EpiLing*' and '*Listening to people with seizures*' project

teams as having used, “a *transcript-based sociolinguistic research method inspired by Conversation Analysis (CA)*” (p43). Similarly, Schwabe and colleagues (2008) have “*readily acknowledged*” that the method of linguistic analysis used by project members has “*differed significantly from traditional CA*” (p61), and is “*in line with the interdisciplinary application of conversation or discourse analytical methodology*” (p69). The authors also considered the approach taken as comparable to the interdisciplinary discourse work of Sarangi and Roberts (1999). Finally, the authors recognised the “*considerable overlap between the linguistic analyses carried out ... and other variants of close linguistic study of human interaction such as Discourse Analysis, Discursive Psychology or narrative analysis*” (p61).

A description of how the two (remaining) qualitative analyses undertaken in this study were carried out is presented below.

2.4.3. Procedure

As previously described, these qualitative analyses, using methods inspired by CA and DA, focused on those phases of the consultations in which patients' seizure episodes were described. Such descriptions were present in four of the topical history-taking phases identified in the data (labelled history-taking phases 4 to 7 in figure 4). These phases had previously been identified and 'marked-up' in the transcripts and became the focus of further analysis. To ensure the conversational and interactional phenomena under study were correctly identified (and where appropriate categorised), several passes of the data (in its entirety) were made during the analyses described below.

A third party transcribed the recordings used in this study. However, the transcripts were analysed alongside recordings of the interactions to ensure correct transcription, and to inform the analyses (for example, in relation to overlap, interruptions and participants body movements). Extracts from transcripts are presented in the results section to illustrate the findings described. Instances of overlap and interruption are explained when relevant to the analysis, indicated by [square brackets] in the transcript. Some participant body language is detailed in the extracts presented; however, this too was only done when relevant to the analysis, indicated by (single rounded brackets) in the transcript.

2.4.3.1 Companion involvement mechanisms

The first fine-grade qualitative analysis in the study explored *how* companions became involved in interactions to 'gain the floor' (for accounts of the 'floor' see Goffman 1967, 1981, 1983 and Edelsky 1981, 1993). Goffman (1981) observed that hearers can intervene in conversation with "*asides, parenthetical remarks and even quips, all of whose point depends upon their not being given any apparent sequence space in the flow of event*" (p29). Following from this, Edelsky (1981) considered that, "*it is possible to take a turn without having the floor*" (p406). In the analysis described here, minimal agreement and acknowledgement tokens (for example, 'continuers' (Schegloff, 1982), 'agreement' (Zimmerman, 1993) and other 'back-channel' remarks (Lambertz, 2011) made by a member of the patient-party were not considered 'floor-taking' activities. Similarly, minimal utterances made by a member of the patient-party that did not alter the "flow of the event" (Goffman, 1981, p29), in so much as the 'story-teller' subsequently resumed their 'story-telling' activity, were not considered 'floor-taking' activities.

Doctors' speech productions and turns-at-talk were considered differently to those of patients and companions. The asymmetry of doctor-patient interactions has been widely recognised; doctors normally control the topical agenda of discussions in medical interactions and are considered the 'dominant speaker' (Frankel, 1990). As Ainsworth-Vaughn (2001) has noted, "*questions are the speech activity usually seen as embodying asymmetry in the encounter*" (p459). In addition, doctors' questions, "*often introduce, develop and dissolve topics*" (Paget, 1993, p123). Similarly, minimal agreement and acknowledgement tokens used by doctors during patient and companion descriptions of attacks were considered important, as they could indicate that the doctor wanted to hear more.

Participants were only considered to have 'gained the floor' to describe what they had experienced/witnessed (to tell 'their story') after they had been 'given the floor' by the doctor. The doctor did this by asking the participant to describe what they had experienced or witnessed, by prompting the participant to continue with their description, or by inviting the participant to clarify or elaborate on something they had said.

The different ways in which companions became involved in interactions and 'gained the floor' to describe what they had witnessed were examined and organised into mutually exclusive categories. The different companion involvement mechanisms identified in the data are summarised in figure 5. Where possible, companion involvement mechanisms were described with reference to whether companion descriptions were typically made (their 'story-telling activities' were done) before or after those of patients.

In the second stage of the analysis, micro-analytic methods akin to those used by conversation analysts were employed to examine the conversations that took place before companions 'gained the floor' to describe what they had witnessed. This involved a sequential analysis of turns-at-talk and the conversational activities of participants leading up to the point at which companions 'gained the floor' to describe what they had witnessed and to 'tell their story'. A core focus of this analysis was patient resistance to doctors' questions about their attacks. From these findings, the interactive consequences of patient resistance for companion involvement – both in terms of the ways in which companions 'gained the floor' and the extent that patients (and subsequently doctors) were reliant on companions to describe what they had seen - were assessed. Potential interactional and conversational pointers that might help differentiate between patients with epilepsy and PNES in accompanied encounters were identified from these analyses.

2.4.3.2 Subjective seizure symptoms

The second fine-grade qualitative analysis in this study explored descriptions of subjective seizure symptoms: what the patient had thought or felt before, during or after a seizure episode.

The extent to which patients with seizures volunteer subjective seizure symptoms when they describe their attacks, and the level of detail attached to these descriptions has been recognised as a diagnostically differential feature of seizure patient talk. People with epilepsy have typically been observed to volunteer details about their subjective seizure symptoms and discuss these in detail when they talk to a doctor about their attacks. In contrast, people with PNES have typically been observed to avoid discussing these symptoms (or to discuss them sparingly), often despite considerable prompting from the doctor

(Guelich and Schoendienst, 1999; Schoendienst, 2001; Furchner, 2002 and Surmann, 2005, cited in Schwabe et al, 2008; Schwabe, Howell, and Reuber, 2007; Plug and Reuber, 2009; Plug, Sharrack and Reuber 2009a, and Reuber and Monzoni, 2009 and Reuber et al, 2009).

Differences between the frequency, use and level of detail attached to subjective seizure symptoms by patients with epilepsy and patients with PNES were not explored in this study. The focus of the analysis was instances where companions described or stimulated discussion of patients' subjective seizure symptoms. Companion descriptions of patients' subjective seizure symptoms were explored to see if they had the potential to influence patient descriptions and/or had the capacity to limit opportunities for patients to describe their subjective seizure symptoms (regardless of whether the patient was subsequently diagnosed with epilepsy or PNES).

Heritage (2012) has described epistemic status as the level of access two (or more) persons have to a domain or territory of information. Since subjective seizure symptoms encompass what a patient thought or felt before, during or after a seizure episode, seizure patients have primary (epistemic) access to this information. If companion descriptions have the ability to influence or limit patient reports of their subjective seizure symptoms, then it is possible that the presence of a companion (and descriptions of what they have witnessed) might adversely affect other previously recognised diagnostically differential markers of seizure patient talk identified in one-to-one interactions between doctors and seizure patients.

Using topical history-taking phases 4 to 7 as a guide for the analysis, all subjective seizure symptoms in the data (made by either the patient or companion) were identified in the first instance. Those made by patients were examined to see if the symptom had previously been discussed in the consultation. Micro-analytic methods (as previously described) were used to examine previous reports of the symptom (if applicable) and the interaction prior to the symptom's mention, to see whether the patient had been stimulated or prompted to discuss the symptom. Likewise, subjective seizure symptoms reported by companions were assessed to see whether the patient had previously discussed the symptom. If the patient had not, then the rest of the interaction was examined to see whether the patient subsequently discussed

the symptom. If the patient did discuss the symptom after the companion had introduced it, the companion's prior account (and where applicable, the questions asked by the doctor) were examined to see if and how they had influenced the patient's account.

3. Results

3.1 Statistical results

Of the 13 patients included in the analysis, six were diagnosed with epilepsy and seven were diagnosed with PNES. As detailed in table 12 below, there was a significant difference in the median lengths of the PNES and epilepsy patient consultations. Correspondingly, there was a significant difference between the total number of words spoken in these consultations.

The epilepsy patient sample was older and contained more male participants than the PNES patient group. However, these differences were not significant and are consistent with these patient groups.

Finally, there was a significant difference in the ratio of PNES and epilepsy patient consultations undertaken by the two doctors participating in these interactions. Of the seven patients diagnosed with PNES, Dr A took part in six consultations and Dr B in one consultation. Of the six patients diagnosed with epilepsy, Dr B took part in all six consultations. Both doctors were consultant neurologists, male, and in their forties.

Table 12: Clinical and demographic features of PNES and epilepsy patient groups

		PNES cases (n=7)	Epilepsy cases (n=6)	Significance
	Median length (minutes)	34.2 (range 11.4 to 58.1)	18.8 (range 10.2 to 24.2)	p0.027*
	Median words spoken	6113 (range 1969 to 11581)	3187.5 (range 1851 to 3386)	p0.027*
Consultation undertaken by:	Doctor A	1	6	p0.005 ^v
	Doctor B	6	0	
Age	20 to 35 years	1	2	p0.405 [^]
	36 to 50 years	4	1	
	51 to 64 years	2	2	
	65+ years	0	1	
Patient gender	Male	3	5	p0.266 ^v
	Female	4	1	
Companion gender	Male	4	1	p0.266 ^v
	Female	3	5	

* Mann-Whitney U test (2-tailed)

^v Fishers Exact Test (2-tailed)

[^] Freeman-Halton extension of the Fisher Exact test (2-tailed)

The median length of the thirteen consultations included in the analysis was 24 minutes. The median total number of words spoken in the consultations was 3386 words.

As detailed in table 13 below, no significant difference was found between the median discourse space occupied by patient parties (the combined verbal activity of patients and companions) (48%) and the median discourse space occupied by doctors (52%). As one would expect, these discourse spaces were perfectly and significantly (inversely) correlated ($r_{s=}$ -1), indicating that as one discourse space increased the other decreased in equal measure and vice-versa. The median discourse space of doctors (52%) was significantly greater than patients (26%) and companions (19%) in the sample. No significant correlation was found between the discourse spaces of doctors and patients, or doctors and companions. Finally, despite patients occupying comparatively more discourse space than companions (median difference 8%), this difference was not found to be significant (p0.562). In addition, a significant (p0.002), strong to very strong ($r_{s=}$ -0.76) inverse association was observed between the discourse space of patients and companions in these interactions.

Table 13: Differences in the discourse spaces of participants in interactions with seizure patients accompanied by their seizure-witness spouse or partner.

Participants	Median proportion* (and range) of words	Participants	Median proportion* (and range) of words	Significance [†]	Correlation coefficient [^]
'Patient parties' ^{>}	48.1% (38% to 74.3%)	Doctors	51.9% (25.7% to 62.1%)	p0.818	$r_s = -1$ (p<0.0001)
Patients	25.9% (11.5% to 62.9%)	Companions	18.3% (8.8% to 46.8%)	p0.562	$r_s = -0.76$ (p0.002)
Companions	18.3% (8.8% to 46.8%)	Doctors	51.9% (25.7% to 62.1%)	p0.003	$r_s = -0.22$ (p0.469)
Doctors	51.9% (25.7% to 62.1%)	Patients	25.9% (11.5% to 62.9%)	p0.020	$r_s = -0.36$ (p0.224)

*Median proportion of words by the participant to the total number of words produced by all participants in the consultation.

[†] Wilcoxon signed-rank test (p)

[^] Spearman's rank correlation coefficient (Spearman's rho) (r_s) and significance (p)

[>] 'Patient parties' are defined as the combined contributions of patients and companions.

In line with Street and Gordon's (2008) methods, companions were defined as occupying 'passive', 'partner', or 'advocate' roles. 54% of companions (n=7) participating in the interactions were identified as 'passive' (contributing less than 40% to patient-party talk), 15% (n=2) were identified as 'partners' (contributing 40% to 60% to patient-party talk) and 31% (n=4) were classified as 'advocates' (contributing more than 60% to patient-party talk). The median contribution of 'passive' companions to patient-party talk was 29% (range 19% to 33%), 'partner' companions 45% (range 44% to 45%) and 'advocate' companions 62% (range 61% to 68%).

As detailed in table 14 below, epilepsy patients occupied moderately more discourse space than PNES patients (5% median difference). In addition, companions of PNES patients occupied comparatively more discourse space than epilepsy patient companions (median difference 8.3%). Finally, a 2% median difference was observed between the verbal activities of doctors participating in PNES and epilepsy patient consultations. However, none of these differences proved statistically significant.

Table 14: Patients with PNES or Epilepsy accompanied by their (seizure witness) spouse: differences in the proportion of the total number of words spoken (%) by participants

Discourse space	PNES	Median proportion* and range	EPS	Median proportion* and range	Significance [†]
Patients	N=7	22.0% (11.5% to 44.1%)	N=6	26.6% (11.6% to 62.9%)	p0.834
Companions	N=7	26.0% (9.5% to 32.7%)	N=6	17.7% (8.8% to 46.8%)	p0.944
Patient-party ^{>}	N=7	48.8% (39.8% to 64.7%)	N=6	46.8% (38% to 74.3%)	p0.834
Doctors	N=7	51.2% (35.3% to 60.2%)	N=6	53.2% (25.7% to 62.1%)	p0.834

*Median proportion of words by the participant to the total number of words produced by all participants in the consultation.

[†]Mann-Whitney U test (2-tailed)

[>]'Patient-parties' are defined as the combined contributions of patients and companions.

3.2 Topical consultation and history-taking phases

Consultation phases akin to those described in previous neurology (seizure) clinic research (Monzoni et al, 2011) were identified in all consultations analysed. These consisted of: (1) opening sequence (introductions), (2) history-taking, (3) diagnosis (firm, tentative, or unknown), (4) etiological explanations of diagnosis (or absence of diagnosis), and (5) recommendations for treatment and/or further tests and management.

These consultation phases were not necessarily consecutive. History-taking discussions in the interactions were not confined to a distinct 'space', and were often interspersed throughout consultations. For example, the delivery of a diagnosis, etiological explanations of diagnosis, and recommendations for treatment and management often sparked discussion of previous events (history). Where diagnoses were tentative or unknown and further tests were required (as in two PNES patient cases and one epilepsy patient case), there was a greater tendency to continue history-taking until the consultation concluded.

History-taking phases were grouped into nine different categories based on topical content, as illustrated below in figure 4.

Figure 4: Topical history-taking phases

<p>(1) Problem presentation. This phase was typified by brief discussion of: a broad classification of the loss of consciousness (for example, seizures or blackouts), and reasons for referral (immediate events leading up to referral (very briefly described) and who made the referral).</p>
<p>(2) Basic patient information. This segment of the consultation was characterised by discussions of: age, occupation, 'handedness' (left or right handed), marital status/living arrangements (including relationship to the companion, if not established during the introduction), driving status, and smoking and alcohol intake.</p>
<p>(3) General medical history. During this phase, current medications and any other medical problems or interventions (past, present or pending) were discussed.</p>
<p>(4) Patient descriptions of seizure event(s). This phase was typified by discussions of patient seizure event experiences. The majority of consultations analysed contained discussions of a patient's first seizure event and most recent seizure event. In addition, some consultations also included discussions of the patient's worst seizure experience or a 'typical' seizure experience. The focus of the discussions ordinarily included descriptions of 'before, during and after' seizure event experiences (these are described in more detail later).</p>
<p>(5) Companion descriptions of seizure event(s). Similar to patient's seizure descriptions, this phase was typified by a focus on what had been witnessed 'before, during and after' seizure events. These descriptions often concerned the patient's first, most recent, worst seizure event and/or a 'typical' seizure event.</p>
<p>(6) Seizure condition chronology and changes in seizure events over time. During this history-taking phase the onset (year of/time passed since the first event,) type, frequency, severity, and pattern of seizure events were discussed.</p>
<p>(7) Other 'funny' or 'unusual' events. This history-taking phase was characterised by discussions of other patient experiences that might have been of significance. For example, participants were observed to discuss topics such as blank spells, periods of absence, isolated jerks, and déjà vu.</p>
<p>(8) Family history. Most of the consultations contained a short distinct segment of discussion about any family history of epilepsy or other loss of consciousness events.</p>
<p>(9) Social history. This history-taking segment was characterised by discussions of the social impact of seizures, including employment, driving, and (if applicable) safety measures.</p>

All of the consultations examined featured the (vast) majority of the history-taking topics detailed above in figure 4.

History-taking phases often began with discussions of (phase 1) problem presentation followed by (phase 2) basic patient information and (phase 3) general medical history. History-taking phases were typically concluded by discussions of (phase 6) seizure condition chronology and changes in seizure events over time, (phase 7) other 'funny' or 'unusual' things, (phase 8) family history and (phase 9) social history topics. Facets of these topical areas were often observed earlier in the consultations. However, even if established previously, these topics were often returned to towards the end of history-taking discussions.

The topic of other 'funny' or 'unusual' things (phase 7) was observed to act as a 'catch-all' for anything else of significance that may not have been covered during the conversation, or to explore previously referenced subjects in more depth. Ordinarily initiated by doctors, this phase appeared to serve as a segment in which the doctor was able to explore features that may not have been considered important or were overlooked by patients or companions in their earlier descriptions (for example, blank spells, periods of absence, isolated jerks, and *déjà vu*). Doctors were also observed to return to seizure chronology discussions (phase 6) towards the end of history-taking discussions, summarising or clarifying what had already been established and (if applicable) exploring any gaps in seizure trajectories. Usually initiated by doctors, this (chronology) phase appeared to serve as a platform from which doctors introduced the topic of diagnosis. Doctors usually initiated questions exploring any family history of seizure disorders before or after these two (phases 6 and 7) phases.

In many of the consultations analysed, history-taking phases concluded after the social history was discussed. Doctors initiated discussion of patients' social histories, often exploring previously referenced features in more depth, and often used these discussions later in the consultations as a platform for management recommendations (for example, mitigating the risks of recreational pursuits, advising patients about driving requirements, and discussing employment issues).

Of the (nine) topical history-taking phases identified, patient and companion seizure event descriptions (phases 4 and 5) were the most widely dispersed, occurring frequently - even if only briefly, throughout all of the other history-taking phases identified. However, most of the substantive (patient and companion) seizure event descriptions occurred midway through the overarching history-taking consultation phase. As mentioned in figure 4, these descriptions typically involved a focus on 'before', 'during' and 'after' seizure event experiences.

'Before the event' discussions ordinarily included descriptions of the circumstances of the event (where the event occurred and what the patient was doing at the time), seizure triggers (including the influence of alcohol or lack of sleep), and warning signs (including physical changes and changes in behaviour). 'During the event' features regularly included discussion of patient motor phenomena (the nature and degree of physical movements), eye movement (open or closed), changes in skin colour, vocalisations, responsiveness (degree of unconsciousness and/or confusion), sickness (vomiting), incontinence, and how long events occurred for (particularly patient unconsciousness, often within a time frame of total events). 'After the event' discussions were characterised by discussion of patient responsiveness (degree of confusion after regaining consciousness), post-seizure symptoms, and time to return to normality.

All companions in the sample described what they had witnessed during specific seizure events or a typical seizure event. Topically, periods of reduced patient consciousness or unconsciousness were a primary focus of seizure-witnesses descriptions.

When they discussed 'gaps' in patient consciousness, companions typically described patient positioning (particularly during seizure onset, for example, sitting or standing), the patient's physical movements (motor phenomena), whether the patient's eyes were open or closed, changes in the patient's skin colour (for example, flushed or pale), any vocalisations, patient responsiveness during the attack (degree of unconsciousness and/or ability to respond) and how long the patient was unconscious for (often within a timeframe of the total seizure episode). As well as describing what had they had witnessed 'during' seizure events, companions usually discussed certain aspects of events that

occurred 'before' and 'after' seizure episodes. For example, companions frequently described seizure warning signs (including physical changes in the patient and/or changes in patient behaviour before the event), and patient responsiveness following the event (patient confusion and awareness, and the time taken for the patient to return to normal).

Some of these topical features are illustrated in extract 6A below. This extract was taken from Mary's consultation, a patient with epilepsy.

Extract 6A.

99. D: ((Tuts)) And um ((2 seconds)) what's the first thing that
100. happens in the attack?
101. C: She screams like.
102. D: OK.
103. C: (()) screams out.
104. D: Yeah.
105. C: Then she like starts, keels over like. She always falls
106. on to her right hand side as well.
((12 lines omitted))
119. D: ((1 second)) And then what's the?
(Doctor shakes his left and right hands to different extents)
120. C: No, your left hand.
121. D: Shaking like?
122. C: She always falls on her left hand side, sorry. Yeah, she
123. always goes that way, falls that way
124. ((0.5 seconds)) cos.
125. D: But what's the screaming, er what's the shaking like?
126. C: Really, really violent, quite violent.
127. D: How, I mean wild limbs or?
128. C: No, like, no, like she.
129. D: (()) (talking together).
(Doctor demonstrates shaking of limbs)
130. C: (()) (talking together) look like that and shaking.
131. D: And that goes on for how long?
132. C: I'd say about a minute, about that.
133. D: Um, and then, and then what happens?
134. C: Then she just passes out and really, does really like
135. slow breathing but really heavy breathing like
136. (Breathes in/breathes out hard)
137. D: Yeah.
138. C: Like that, really, really out of it, about two minutes, then
139. she wakes up and she's oh like ((1 second)) and
140. haven't got a clue where she is. ((laughs))
141. D: And how long does that section go on for?
142. C: This lasts about, see it takes about five minutes after
143. that to come round. Oh it takes about ten minutes
144. altogether before she's like really knows where she is
145. and what's happened.

In the extract above, the companion described Mary's vocalisations at the beginning of an attack, "she screams" (line 101), "screams out" (line 103). He also described Mary's positioning at the beginning of an attack, "keels over" (line 105), "always falls on to her right hand side" (lines 105 to 106), "always falls on her left hand side, sorry. Yeah, she always goes that way, falls that way" (lines 122 to 123). Mary's physical movements were also discussed, the companion described her shaking as, "really, really violent, quite violent" (line 126). When the doctor demonstrated different types of shaking with his hands and limbs (see lines 119 to 120 and 129 to 130), the companion identified the level of movement that ordinarily occurred, "no, your left hand" (line 120) and "look like that and shaking" (line 130). Following this, the companion described the length of time Mary's shaking typically went on for ("about a minute", line 132).

Later, the companion discussed Mary's level of consciousness and her typical breathing pattern after the shaking had subsided, "passes out and really, does really like slow breathing but really heavy breathing" (lines 134 to 135), and demonstrated this, "((breathes in/breathes out hard))" (line 136). The companion then discussed different grades of Mary's consciousness following an attack ("really, really out of it", line 138, "wakes up", line 139, "come round", line 143), her responsiveness following a seizure event ("haven't got a clue where she is", line 140, "really knows where she is and what's happened", lines 144 to 145), and how long it took Mary to return to normality ("two minutes, then she wakes up", lines 138 to 139, "five minutes after that to come round", lines 142 to 143, "ten minutes altogether", lines 143 to 144).

Descriptions of patients' attacks, and discussions of periods of reduced patient consciousness and unconsciousness primarily took place during topical history-taking phases 4 and 5. However, these discussions were also observed during talk about the patient's seizure chronology (phase 6), for example, descriptions of changes in the nature of seizures over time, and conversations about other, 'funny' or 'unusual' events (phase 7), for example, patient blank spells, brief periods of absence, and isolated jerks. As previously discussed, these four history-taking phases (phases 4 to 7) were the focus of the finer-graded qualitative analyses described below.

3.3 Companion involvement mechanisms

Companions became involved in interactions and ‘gained the floor’ to describe what they had witnessed in three main ways; they self-initiated, they were invited by the doctor, or they were invited by the patient.

A summary of these mechanisms (and sub-mechanisms) is presented below in figure 5.

Figure 5: Companion involvement mechanisms summary

Companion involvement mechanisms
1) The companion was invited by the doctor
(a) After the patient had described at least one seizure event, the doctor invited the companion to describe what they had witnessed.
(b) The patient did not volunteer and was not invited by the doctor to provide a seizure event description. The doctor invited the companion to describe what they had witnessed, ‘bypassing’ the patient.
(c) The patient resisted describing what had happened during attacks, often despite considerable prompting from the doctor, and the doctor invited the companion to describe what they had witnessed.
2) The companion was invited by the patient
The patient resisted describing their experiences (often despite considerable prompting from the doctor) and invited or prompted their companion to describe what they had seen. The companion responded to the patient’s invitation, and the doctor allowed the companion to describe what they had witnessed (for example, by prompting the companion to continue, or by inviting the companion to clarify or elaborate on something they had said).
3) The companion self-initiated
The patient had limited opportunity to describe what they had experienced during attacks because their companion repeatedly intervened (self-initiated, including taking the patient’s turn). The doctor allowed the companion to describe what they had witnessed, by prompting the companion to continue, or by inviting the companion to clarify or elaborate on something they had said.

1) The companion was invited by the doctor

(1a.) After the patient had described at least one seizure event, the doctor invited the companion to describe what they had witnessed

An attempt to conform to a 'preferred' history-taking structure was evident in the majority of the consultations analysed. In this structure, the companion was invited by the doctor to describe what they had witnessed after the patient had provided a description of their experience.

Patients in consultations that adhered to this structure typically demonstrated low levels of resistance to doctors' questions about their attacks. In these interactions, patient resistance to doctors' questions was usually a consequence of the potentially problematic design of the question posed, rather than the doctor's topical agenda. In response to potentially problematic question designs, patients in these encounters typically 'specified' the terms of the question (Stivers and Hayashi, 2010), and/or provided an 'extended answer' (Stivers and Heritage, 2001) or 'roundabout trajectory' (Clayman, 2001).

Patients in these interactions sometimes prompted their companion to confirm an account of what they had experienced, but rarely (if ever) deferred to their companion to answer the doctors' questions on their behalf. Patients (and subsequently doctors) were at least moderately reliant on companions to describe what had happened during periods of reduced patient consciousness or unconsciousness in all the interactions examined. However, patients who participated in the type of interaction described here were comparatively less reliant on their companion to describe what they had witnessed than patients in the other types of interactions identified.

When patients described their experiences, companions in these encounters tended to volunteer minimal agreement and acknowledgement tokens (for example, 'continuers' (Schegloff, 1982), 'agreement tokens' (Zimmerman, 1993) and other 'back-channel' remarks (Lambertz, 2011)). Disregarding these, companions did sometimes self-initiate to become involved in the conversation, however, this was often after the patient had demonstrated difficulty describing their experience or responding to a question from the doctor. Beyond this, companion self-intervention was typically minimal; companions rarely (if ever) volunteered an account of what they had witnessed without being asked by the

doctor, and they rarely interrupted the patient or took the patient's turn to answer the doctor's question on the patient's behalf.

This type of structural organisation (and associated interactive behaviours) was observed in three of the six epilepsy patient consultations analysed and in one of the seven PNES patient consultations, Lawrence's. This organisation and examples of the participant behaviours outlined above are illustrated below in extract 6B. The extract is taken from Stephen's consultation, a patient with epilepsy.

The key moment in extract 6B takes place at line 61, when the doctor invited the companion to describe what she had witnessed. Before this invitation, the companion had had minimal involvement in the conversation. After she had been invited by the patient to do so, the companion did elaborate on something the patient had said (at line 45 and lines 47 to 48). At line 54, the companion also responded to patient difficulty (at lines 52 to 53). However, the companion only 'gained the floor' to describe what she had witnessed after she had been invited by the doctor to do so (at line 61).

Extract 6B

30. D: Has anything happened since?
31. P: Well ((1 second)) I've still, I've had a couple of
32. blackouts.
33. D: Right.
34. P: And er I'm getting headaches every day, but the
35. headaches they, aren't all way round me head, from
36. this.
(Patient points to the side of his forehead)
37. D: What, and what, have you bashed yourself, or?
38. P: I've had this ten years but it's been a little lump, that
39. was all, and up to the last, how long ago, six month?
40. C: Mm.
41. P: It's come up like that, and when I'm getting this
42. headache it's all round here, and when it gets really
43. bad I'm getting a burning feeling at the back of me
44. eye and er gradually me eye closes don't it?
45. C: And it drops.
46. P: I can't keep me eye open.
47. C: It just looks like he's having a stroke cos his eye just
48. drops when he's, when it's going on.
49. P: And then if I bend over or owt, I go, I'm out.
50. D: ((1 second)) So you pass out when you're bending
51. over?
52. P: Yeah, well er ((0.5 seconds)) the last time I had it
53. when I'd just come, er ((0.6 seconds))
54. C: It's not all (the) time is it?
55. P: No, no, I, since I've been back out of hospital I've
56. had, what, three, three, that's all.
57. D: And it's always when you're bending over you get
58. this?
59. P: Yes, when I've had, I've got that pain and that,
60. yeah.
61. D: Um, and you've seen some of the [blackouts?]
(Doctor turns his head to face the companion)
62. C: [Normally when]
63. P: One when, when I got up off of settee after I'd been
64. doing that paperwork.
65. C: Oh yeah, yeah.

The talk before that shown in extract 6B concerned a very brief discussion of the date and circumstance of Stephen's first seizure experience after he was administered anaesthesia for a minor operation (Stephen had no recollection of this event). During that account, Stephen's companion had minimal involvement in the conversation; she occasionally used minimal agreement or acknowledgement tokens, such as 'mm', 'mmm', 'mhm', 'yeah' (for example, as at lines 40 and line 65 in the extract shown, "mm").

Extract 6B starts at line 30, where the doctor asked Stephen, “Has anything happened since?” The ‘polar design’ (Raymond, 2003) of the doctor’s question appeared to warrant a yes/no response. However, the patient appeared to find the design of the doctor’s question problematic. Following an initial response of “Well”, Stephen’s hesitation and subsequent reformulation of his answer “((1 second)) I’ve still, I’ve had” (line 31) indicated that Stephen had a problem responding to the question posed. As Schegloff and Lerner, (2009) have observed, responses that begin with ‘well’ (“Well”, line 31) usually signal that a response is not going to be straightforward.

However, Stephen’s resistance appeared to stem from the potentially problematic design of the question posed, rather than the question’s topical agenda. At line 30, the doctor used the term “anything” in his question. Given the context of the conversation, it seems likely that the topical agenda of the question was Stephen’s ‘seizures’ (or ‘blackouts’, etc.) However, the doctor did not make this explicit, and Stephen may have considered the question ambiguous.

In his response, Stephen ‘narrowed’ or ‘specified the terms’ (Stivers and Hayashi, 2010) of the doctor’s question. In the first instance, Stephen responded by describing his present situation (“I’ve still”, line 31). However, Stephen subsequently reformulated his response and described what had happened since his first ‘blackout’ (“I’ve had”, line 31), he re-aligned his response with the terms of the doctor’s question (“happened since”, line 30). Stephen ‘specified the terms’ of the question posed (“anything”, line 30), by specifically discussing the number of ‘blackouts’ he had experienced since the first event, “Well ((1 second)) I’ve still, I’ve had a couple of blackouts” (lines 31 to 32).

After the doctor had acknowledged and aligned with Stephen’s initial response (“right”, line 33), Stephen elaborated on his answer and discussed the symptoms (‘headaches’) he had experienced (lines 34 to 36). During this explanation, Stephen linked the origin of his ‘headaches’ to the ‘lump’ on his forehead (“from this”, lines 35 to 36, and “[Patient pointed to the side of his forehead]”, lines 36 to 37).

Following this, the doctor asked, “What, and what, have you bashed yourself, or?” (line 37). This question could be seen as potentially problematic. The doctor’s question began with, “What, and what” (line 37). The doctor subsequently reformulated the question to a ‘polar design’ (Raymond, 2003), “have you bashed yourself” (line 37). However, the doctor latterly added “or” (line 37) to the end of the question, and thus opened up other possibilities of patient response.

In his response, Stephen initially reported how long he had had the ‘lump’, (“I’ve had this ten years”, line 38), adding that the ‘lump’ had not always been as large, “but it’s been a little lump, that was all” (lines 38 to 39). Stephen then framed the period in which the lump had grown (later evidenced by “it’s come up like that”, line 41), and turned to his companion for confirmation, “and up to the last, how long ago, six month?” (line 39). The companion confirmed this with a minimal response, “mm” (line 40).

Stephen then discussed the headaches he experienced, and added some subjective detail, “a burning feeling” (line 43). Stephen then prompted his companion to confirm his account, “and er gradually me eye closes don’t it?” (line 44). With a minimal response, Stephen’s wife confirmed and elaborated on his account, “and it drops” (line 45). Following this, Stephen continued to discuss the extent that his eye closed when he had a headache, “I can’t keep me eye open” (line 46). This was followed by Stephen’s wife reiterating and elaborating on her initial observation, “It just looks like he’s having a stroke cos his eye just drops” (lines 47 to 48).

Stephen’s (and his companion’s) responses did not directly answer the doctor’s question, “What, and what, have you bashed yourself, or?” (line 37). However, the question was answered indirectly, using what Clayman (2001) has called a ‘roundabout trajectory’. Similarly, Stivers and Heritage (2001) have observed that one-way patients address potentially problematic responses to doctors questions is by expanding their answers. In the absence of talk that discussed, for example, Stephen ‘banging’ or ‘bashing’ his head, a narrative developed that indicated the lump had grown over time.

In Stephen's and his companion's accounts, Stephen's 'headaches' were specifically linked to Stephen's 'lump', "when I'm getting this headache" (lines 41 to 42) and "when he's, when it's going on" (line 48). Stephen was later observed to link these symptoms to seizure ('blackout') triggers and occurrence, "and then if I bend over or owt, I go, I'm out" (line 49).

At lines 50 to 51, the doctor asked Stephen, "((1 second)) So you pass out when you're bending over?" However, Stephen (and his companion) appeared to find the design of the doctor's question (and those that followed) potentially problematic. The doctor's question may have implied that 'every time' Stephen bent over he passed out. At line 52, Stephen began his initial response with a confirmation, "Yeah". This appeared in keeping with the 'polar design' (Raymond, 2003) of the doctor's question. However, Stephen's initial response (of "Yeah", line 52) was qualified with "well" (line 52), and signalled his response was not going to be straightforward (Schegloff and Lerner, 2009). Stephen then attempted to answer the question by using an example and describing his last experience, "the last time I had it when I'd just come" (lines 52 to 53). However, prior to and following this response Stephen hesitated, "er (0.5)" (line 52) and "er (0.6)" (line 53), suggesting he found providing a response difficult.

In what appeared to be in response to this difficulty, the companion intervened and 'specified the terms' (Stivers and Hayashi, 2010) of the doctor's question. She reintroduced timing as a consideration, "It's not all (the) time is it?" (line 54). The companion's response linked the potential problematic design of the doctor's question (a possible assumption of 'every time') to the patient's initial response to the question, "last time" (line 52).

In response, Stephen confirmed his companion's account, "no, no" (line 55), and went on to discuss how many seizures he had experienced since leaving hospital, "I, since I've been back out of hospital I've had, what, three, three, that's all" (lines 55 to 56). Stephen's description of "three, three, that's all" (line 56) appeared to suggest that he could not have possibly 'passed out' 'every time' he had bent over since he was discharged.

However, the doctor's subsequent question was also treated by the patient as problematic and as requiring qualification. The doctor reformulated his prior question, and asked, "And it's always when you're bending over you get this?"

(lines 57 to 58). However, this question appeared to implicitly link 'bending over' to 'passing out'; the doctor used the term, "always when" (line 57).

Stephen responded to the doctor's question by initially answering, "Yes" (line 59). However, Stephen's answer was later qualified with, "when I've had, I've got that pain and that" (lines 59 to 60). This qualification framed the 'bending over' and 'passing out' as only having occurred when he had experienced the symptoms previously discussed ('pain' and 'headache'). After this qualification, Stephen again confirmed the doctor's question, "yeah" (line 60). Following Stephen's response, his companion volunteered, "normally when" (at line 62), this may have been the beginning of a qualifying remark. However, the turn was not completed (and was done in overlap with the doctor's question at line 61).

After the discussion about 'bending over' was concluded, the doctor asked the companion, "Um, and you've seen some of the blackouts?" (line 62). Despite the question being intended for the companion ("you've seen", line 62), the patient responded. This may have been in part because of the overlap between the doctor and companion's talk at lines 61 and 62. Nevertheless, Stephen answered that the companion had 'seen' "one" (line 63). It is not clear whether Stephen used the term "one" to indicate that his companion had only witnessed 'one' as opposed to multiple ("some", line 62) events, or whether Stephen wanted his companion to discuss a specific event, "one when, when I got up off of settee after I'd been doing that paperwork" (lines 63 to 64). In response, the companion confirmed the patient's account "Oh yeah, yeah" (line 65), and went on to describe what she had witnessed (not shown in the abstract).

Stephen demonstrated low levels of resistance to the topical agenda of the doctor's questions, appearing rather to strive to answer the doctor's questions and provide answers that adhered to the topical agenda of the questions. When Stephen did seem to resist questions, this was typically a consequence of the potentially problematic design of the doctor's questions. In response, the patient (and where applicable, the companion) tended to 'specify the terms' (Stivers and Hayashi, 2010), of the questions posed and/or provided 'extended answers' (Stivers and Heritage, 2001) or 'roundabout trajectories' (Clayman, 2001).

Finally, Stephen did not appear overly reliant on his companion to describe what she had witnessed. Stephen prompted his companion to confirm or elaborate on his accounts, but he did not defer to his companion to answer the doctor's questions on his behalf. Throughout the encounter, the companion used minimal agreement and acknowledgement tokens; however, the companion rarely self-initiated otherwise, unless Stephen demonstrated difficulty answering. Similarly, the companion did not take the patient's turn or answered the doctor's questions on the patient's behalf.

(1b.) The doctor invited the companion to describe what they had witnessed, 'bypassing' the patient.

In two of the consultations, patients did not describe their seizure experiences, and the companions alone described what had happened during attacks. The doctor involved in these interactions 'bypassed' a patient description of their seizure experience and invited the companion to describe what they had witnessed. However, in both cases it was established that the patients (Klaus and Simon) exclusively experienced seizures from sleep (both patients were subsequently diagnosed with epilepsy).

Despite not providing an account of their seizure experiences, the patients in these two interactions typically demonstrated a low level of resistance to the topical agenda of the doctor's questions. However, they did sometimes find the design of the doctor's questions problematic. Klaus and Simon typically handled potentially problematic questions by 'specifying the terms' (Stivers and Hayashi, 2010) of the questions posed, and by 'expanding' their answers (Stivers and Heritage, 2001) or providing 'roundabout trajectories' (Clayman, 2001).

Their companions frequently used minimal agreement and acknowledgement tokens, but rarely volunteered other talk unless invited by the doctor (and to a lesser extent, the patient) to comment. When the companion did volunteer other talk, this was generally because the patient had demonstrated difficulty providing or elaborating on a response to the doctor's question. Nevertheless, at least from the doctor's perspective, Klaus and Simon were significantly (if not wholly) reliant on their companions to describe what they had witnessed. In the two encounters, the doctor asked the companion to describe what they had

seen shortly after learning that the patient experienced seizures whilst they slept.

This organisational structure (and associated participant behaviours) can be seen in extract 6C, below. The extract is taken from Klaus's consultation, a patient with epilepsy. Key moments in extract 6C occur at lines 51 to 52, where the patient reported that all his seizures had occurred whilst he has slept; and at line 57, when the doctor asked the companion to describe what she had witnessed (as opposed, for example, to inviting the patient to describe what he could remember about the experience).

Extract 6C.

49. D: ((3 seconds)) So um this first attack um was in sleep,
50. falling asleep, is that right?
51. P: Every one I've had have er been while I've been
52. falling asleep.
53. D: (()) (talking together)
54. P: That's correct.
55. D: And you've had four in total?
56. P: Four in total, yeah.
(The doctor turns his head to face the companion)
57. D: Um, what actually happens?
58. P: [Er, wife] know more about it than I do
(The doctor turns his head to face the patient)
59. C: [He's er.]
60. D: That's usual, yes.
[Doctor turns their head back to face the companion]
61. C: He just starts the sort of gurgling and then he goes
62. really stiff, you know.
63. D: And then does he shake after that or is it just stiff?
64. C: It, it, really stiff, and then he sort of calms down and
65. then I have to bring him round from his deep sleep.
66. He goes into a really deep sleep then.
67. P: Yeah. I usually bite my tongue and er wet the bed as
68. well.
[Doctor nods head, makes notes, then returns to face the companion]
69. D: ((5 seconds)) How long is he stiff for?
70. C: Probably just a few seconds. Seems like minutes but
71. I think it's just a few seconds.
(Doctor turns their head to face the patient)
72. D: OK. Um, and you've never had any problems like this
73. in the past?
74. P: No.
75. D: Anything happen during the day?
76. P: No, no.
77. D: No funny things happen to you, stare into space or
78. anything like that?
79. P: Not that I know of, no. (Patient gazes at the companion)
80. C: No.

In extract 6C the doctor asked Klaus about his first seizure experience, “So um this first attack um was in sleep, falling asleep, is that right?” (lines 49 to 50). The doctor specified the seizure as the “first attack” and questioned whether it was experienced “in sleep, falling asleep”. The question was concluded with a ‘polar design’ (Raymond, 2003), “is that right?” However, Klaus appeared to have a problem with the design of the doctor’s question, as was evident in his ‘specifying the terms’ (Stivers and Hayashi, 2010) of the question and giving an ‘expanded answer’ (Stivers and Heritage, 2001).

The doctor questioned the “first attack” (line 49); however, Klaus transformed the terms of the question and described all the seizures he had experienced, “every one I’ve had” (line 51). In addition, the doctor’s question presented two options of seizure occurrence, “in sleep” (line 49) and “falling asleep” (line 50), which was observed to run counter to the ‘polar design’ (Raymond, 2003) of the question posed, “is that right?” (line 50). Klaus handled this by specifying that the attacks had occurred whilst “falling asleep” (line 52). The patient, therefore, demonstrated a low level of resistance to the question posed, and this was in relation to the potentially problematic design of the doctor’s question, as opposed to the topical agenda of the question posed.

Similarly, in the talk that immediately followed this exchange, Klaus did not appear resistant to the doctor’s questions. Unfortunately, the talk at line 53 was inaudible. However, the patient was observed to answer, “that’s correct” at line 54. In response to the doctor’s question at line 55 (“And you’ve had four in total?”), Klaus responded by confirming and repeating the terms of the doctor’s question, “Four in total, yeah” (line 56).

Following this exchange, the doctor turned his head to face the companion (at line 56) and asked, “Um, what actually happens?” (line 57). Despite the question having been intended for his companion, Klaus responded by stating, “Er, wife know more about it than I do” (line 58). This was done in overlap (starting at “Er”, line 58) with the beginning of his companion’s response at line 59, “He’s er”. The doctor responded to the patient’s remark, made at line 58, and commented, “That’s usual, yes” (line 60). This response appeared to highlight that it was common for the companion (seizure witness) to have greater access

to information about what had happened when seizures had occurred from sleep.

However, Klaus's comment indicated that he did remember 'something' about his seizures, although his wife may have "know[n] more" (line 58). This was made evident when Klaus elaborated on his companion's response and discussed what he remembered after a seizure had occurred, "Yeah. I usually bite my tongue and er wet the bed as well" (lines 67 to 68).

At lines 60 to 61 the doctor turned back to face the companion, again indicating that the question to which Klaus responded (at lines 56 to 57) was indeed intended for his companion. After the companion described what she witnessed (see lines 61 to 66), Klaus confirmed and elaborated on her account (lines 67 to 68). The doctor acknowledged this information. At lines 68 to 69, the doctor nodded his head and made some notes in the patient's medical record. However, Klaus was not questioned further on the matter and the doctor continued to elicit a description from the companion, "How long is he stiff for?" (line 69).

The doctor returned to question Klaus at lines 72 to 73. There, and in response to the doctor's question at line 75, the patient did not display resistance to the doctor's questions. Klaus answered, "no" (line 74) and "no, no" (line 76). However, it did appear that the doctor considered the response to his question at line 75 ("Anything happen during the day?") as requiring qualification. Even though the patient answered "no, no" (at line 76), the doctor reformulated and narrowed the terms of his question. This may have been because the doctor's open question at line 75 ("Anything happen during the day?") was insufficiently specific and/or was met with minimal patient response.

The doctor subsequently reformulated the question to, "No funny things happen to you, stare into space or anything like that?" (lines 77 to 78). In response to that question, the patient confirmed his earlier answer (at line 76), but with an added caveat, "Not that I know of, no" (line 79), which appeared to suggest that Klaus was not entirely certain. In addition, Klaus was observed to glance at his companion when he answered. Possibly as a response to this uncertainty, and having been in a position to observe the patient's behaviour, the companion confirmed the patient's response at line 80, "No".

The extract shows that Klaus demonstrated low resistance in answering the doctor's questions. Klaus's resistance was chiefly concerned with the potentially problematic design, as opposed to the topical agenda of the doctor's questions. Klaus typically dealt with the potentially problematic design of the doctor's questions by 'specifying the terms' (Stivers and Hayashi, 2010) of the question posed and/or by providing 'expanded answers' (Stivers and Heritage, 2001). In the consultation, Klaus's companion occupied a 'back seat' until she gained the floor and was invited by the doctor to describe what she had witnessed (at line 57). Before this the companion had only volunteered minimal agreement and acknowledgement tokens (for example, as at line 80).

Finally, as described, the patient appeared to demonstrate knowing something about his attacks, and volunteered talk about what he was aware of after a seizure; "I usually bite my tongue and er wet the bed as well" (lines 67 to 68). However, at least from the doctor's perspective, he and Klaus were almost wholly reliant on the companion to describe what had happened during Klaus's seizures, for example, Klaus's vocalisations ('gurgling", line 61) and body movements ("stiff", lines 62, 63 and 64, "shake", line 63). The doctor invited the companion to describe what she had seen shortly after learning that Klaus experienced seizures whilst he slept.

(1c.) The patient resisted describing what had happened during attacks, often despite considerable prompting from the doctor, and the doctor invited the companion to describe what they had witnessed.

In a number of consultations patients repeatedly resisted answering questions about their seizure experiences, often despite considerable prompting from the doctor to do so. Patients in these interactions frequently resisted the topical agenda of the doctor's questions. They often reported an inability to remember what had happened during attacks and/or 'transformed the topical agenda' (Stivers and Hayashi, 2010) of the doctor's questions. Consequently, many of the patients' responses were characterised as 'negative responses' (Clayman, 2001) and/or 'non-answer responses' (Stivers and Robinson, 2006).

In these interactions, companions used minimal agreement and acknowledgement tokens, but these appeared to be offered less frequently than in the consultations described earlier. Companions 'gained the floor' to describe

what they had witnessed in these interactions after patients had repeatedly resisted describing their experiences, often despite considerable prompting from the doctor to do so, and the companion was invited by the doctor to describe what they had seen. This often meant that companions described what they had witnessed before the patient had described the experience, and in some of the interactions, a patient account of the seizure event under discussion was not provided. Consequently, patients (and doctors) in these interactions appeared significantly reliant on companions to describe what they had seen.

This pattern of companion involvement was observed in four of the seven PNES consultations, but was not observed in any of the epilepsy patient consultations analysed. This interactive organisation (and associated participant behaviours) can be seen in extracts 6D below, taken from Adele's consultation, a patient diagnosed with PNES. The extract presented is spilt up and discussed in three sections (6Di, ii and iii).

In extract 6Di below, key moments take place at lines 26 to 27, 30, 33 to 34, and 36 to 37, where the patient demonstrated resistance to the doctor's questions about her seizure experiences and/or reported an inability to remember what had happened.

Extract 6Di.

26. D: So these, when, when, when was your last seizure?
(Patient turns to face at the companion)
27. C: ((1 second)) Sunday.
28. P: Sunday.
29. D: Mm. ((4 seconds)) What can you tell me about that?
30. P: Um, I don't really remember a lot about them.
31. D: Mm hmm.
32. P: Um ((4 seconds)) kind of very, very tired afterwards.
33. Don't really remember the event before ((1 second))
34. leading up to it.
35. D: Mm.
36. P: Um ((3 seconds)) obviously while I'm having a seizure, I
37. never remember what happens during a seizure ((1
38. second)) and then normally I need to just sleep.

In the extract above, the doctor asked Adele, "So these, when, when, when was your last seizure?" (line 26). However, in response to the doctor's question directed to her, Adele remained silent and turned to face her companion, who after a one second pause answered, "Sunday" (line 27), which was

subsequently repeated by the patient (“Sunday”, line 28). Adele did not request that her companion should answer the doctor’s question, but appeared to prompt her companion to do so by not responding and turning to face him, signifying that Adele could not, or did not want to, answer the doctor’s question.

After the day/date of the event was established (“Sunday”, lines 27 and 28), the doctor acknowledged the responses with a minimal token, “Mm”, followed by a four second pause (line 29). Given that the doctor continued to look at the patient-party, the pause appeared to indicate that the doctor expected the patient (or possibly the companion) to continue. However, the ‘polar design’ (Raymond, 2003) of the doctor’s question (at line 26) may have been considered by the recipient(s) as only warranting a minimal answer.

Following the pause, the doctor asked Adele, “What can you tell me about that?” (line 29). Adele’s response indicated a high level of resistance to the doctor’s question, she reported that, “Um, I don’t really remember a lot about them” (line, 30). Adele responded by reporting an inability to remember. These types of response have been called ‘non-answer responses’ (Stivers and Robinson, 2006) and ‘negative responses’ (Clayman, 2001).

In addition, Adele ‘transformed the terms’ (Stivers and Hayashi, 2010) of the doctor’s question, from one that asked what the patient could tell the doctor (“tell me”, line 29) about a specific seizure (“Sunday”, lines 27 and 28 and “about that”, line 29), to a response that highlighted what she could ‘remember’ (“remember”, line 30) about her seizures more generally (“them”, line 30). Adele’s response suggested that she did not want to, or could not, focus on and describe a specific seizure trajectory, she also ‘transformed the topical agenda’ (Stivers and Hayashi, 2010) of the question to a degree.

After Adele’s initial response had been acknowledged by the doctor (“mm hmm”, line 31), she continued with her description, albeit with hesitation (“Um ((4 seconds))”, line 32). Adele briefly described her symptoms following a seizure, “very, very tired afterwards” (line 32). However, the focus of her description was (again) characterised by what she could not remember. Following her description of ‘tiredness’, Adele reported that, “Don’t really remember the event before ((1 second)) leading up to it” (lines 33 to 34).

In her response, Adele cited an inability to remember. However, her “don’t really remember” response was not straightforward. As observed by Paradis (2003), when ‘really is preceded by negation’, the role of ‘really’ is to de-emphasise; the emphasising force of ‘really’ is reversed and the effect becomes diminished. Adele’s use of “don’t really” de-emphasised the boundary between what Adele could and could not remember, and resulted in a ‘hedged statement’ (Paradis, 2003). Adele’s response indicated that she might have remembered something about the beginning of her seizures.

Adele’s stance about what she could or could not remember about what had happened during her seizures was significantly ‘upgraded’ in her following response. Adele claimed that she could not remember anything about what had happened during her seizures, “Um ((3 seconds)) obviously while I’m having a seizure, I never remember what happens during a seizure” (lines 36 to 37). Adele’s use of “obviously” suggested that her response would be easily perceived or understood, and may have been used to normalise or legitimise her response. There appeared to be an expectation that her response was not subjective, but rather universally acknowledged. Her use of “never” also reinforced the (absolute) degree to which she could not remember what had happened, which can be characterised as an ‘overt’ and ‘strong negative response’ (Clayman, 2001).

In her responses, Adele repeatedly used “Um” (lines 30, 32 and 36) and there were notable pauses at the beginning of her turns (for example, at lines 32 and 36). These features suggest that Adele may have found providing the responses she gave difficult.

The extract presented above shows that Adele was very resistant to discussing a specific seizure trajectory and her seizure experiences more generally. Adele ‘transformed the terms’ of the doctor’s question so that she did not focus on an individual seizure trajectory. In addition, she transformed the ‘topical agenda’ of the doctor’s question by rejecting its underlying assumption (Stivers and Hayashi, 2010) that she could remember something about her seizure experiences. Adele’s responses were also characterised by an inability to remember, particularly about what had happened before and during her seizures. The majority of Adele’s responses were ‘non-answer responses’ (Stivers and Robinson, 2006). In addition, many amounted to what Clayman

(2001) has termed 'strong negative responses', in which the evasion to answering the question was 'overt'. In addition, Adele offered scant detail about what she typically felt like following a seizure; "very, very tired afterwards" (line 32) and "normally I need to just sleep" (line 38). It is also notable that Adele deferred to her companion to answer a question about the date of her last seizure (lines 26 to 28), without attempting to answer this herself.

Adele's resistance to the doctor's questions about her seizures (and her inability to remember what had happened) is also evident in extract 6Dii below. In the extract, key moments occur at lines 48, and 53 to 54, where Adele (again) resisted the doctor's questions about her seizure experiences. Following this, another key moment occurs at lines 58 to 60, where the doctor asked the companion to describe what he had witnessed.

Extract 6Dii.

- ((9 lines omitted))
47. D: But you are aware of the vomiting are you?
48. P: No, not always.
49. D: So sometimes you can vomit before you've regained
50. awareness?
51. P: Mm hmm.
52. D: And sometimes you can remember a little bit about?
53. P: Um ((1 second)) I would say I don't remember, to be
54. honest.
55. D: Mm hmm.
56. P: I only know cos normally there's a bucket there when
57. ((0.5 seconds)) I wake.
(Doctor turns to face the companion)
58. D: ((5 seconds)) So ((0.5 seconds)) when she vomits, does
59. she vomit into the bucket? Does she aim at the bucket
60. or?
61. C: Yeah, she's vaguely with it.
62. D: Mm.
63. C: She knows she's gonna be sick and will sit up and lean
64. over the bucket.
65. D: Mm.

In the extract shown above, the doctor asked Adele whether she was aware she vomited during her attacks (prompted by a comment made earlier in the conversation, not shown), "But you are aware of the vomiting are you?" (line 47). In response, Adele initially conformed to the 'polar design' (Raymond, 2003) of the doctor's question, but gave a 'dispreferred' response, "No" (line 48). The initial design of the doctor's question indicated that the doctor believed

Adele was aware, “But you are aware”, although the addition of “are you” (line 47) at the end of the question opened up the possibility that this may not have been the case.

In her response, Adele elaborated on her initial answer (“No”) with “not always” (line 48). However, this response was ambiguous, it suggested that Adele was sometimes aware. The doctor appeared to deal with this ambiguity by reformulating and specifying the terms of his question, “so sometimes you can vomit before you’ve regained awareness?” (lines 49 to 50). To which Adele responded with minimal agreement, “Mm hmm” (line 51).

In what appeared an attempt to address the ambiguity of Adele’s first response and her second minimal response, in his following question the doctor asked, “And sometimes you can remember a little bit about?” (line 52). In response, Adele delayed answering (“um ((1 second))”, line 53); possibly signalling a ‘dispreferred response’ was to follow (Robinson and Bolden, 2010). Adele then said, “I would say I don’t remember, to be honest” (lines 53 to 54). Adele began her response with, “I would say I don’t remember”, which indicated an epistemic stance. The use of “I would say” firmly set Adele’s response as ‘from her perspective’ or ‘in her opinion’, and appeared to suggest that her perspective might not have aligned with those of others. It is also notable that Adele used the phrase “to be honest” (lines 53 to 54) in her response. As Edwards and Fasulo (2006) have observed, ‘honesty phrases’ frame the assessment as personal to the speaker, imply a ‘truth value’ and often occur when answers are unexpected or questionable. Adele’s response was also clearly characterised by an inability to remember.

Following a minimal acknowledgement response from the doctor (“Mm hmm”, line 55), Adele elaborated on her inability to remember what had happened, by discussing how she knew that she usually vomited during seizures, “I only know cos normally there’s a bucket there when ((0.5 seconds)) I wake” (lines 56 to 57). As Stivers and Robinson (2006) have observed, ‘non-answer responses’ are often accompanied by accounts for not answering questions.

Following this exchange, the doctor turned to face Adele’s companion to ask him about Adele’s awareness and state. Adele’s prior responses (here and in extract 6Di) were characterised by ambiguity and uncertainty, and Adele offered

little information about her experiences. Despite considerable prompting by the doctor, Adele made little attempt to construct an account of what she could remember. The primary focus of Adele's responses was her inability to remember, which in the main were classified as 'non-answers' (Stivers and Robinson, 2006) and '(strong) negative' responses (Clayman, 2001). After a five-second pause (line 58), during which the doctor wrote in the patient's medical records, the doctor asked the companion, "So ((5 seconds)) when she vomits, does she vomit into the bucket? Does she aim at the bucket or?" (lines 58 to 60). At this point, the companion was given the floor to describe what he had witnessed.

The design of the doctor's initial question ("does she vomit into the bucket", lines 58 to 59) was 'polar' (Raymond, 2003). However, the doctor added a subsequent question ("does she aim at the bucket", line 59). In addition, the addition of "or?" (line 60) opened up other possibilities of companion response. In his response, Adele's companion initially confirmed that Adele did vomit "into" or "aim at" the bucket ("Yeah", line 61). The companion also appeared to read the underlying topical agenda of the doctor's question when he elaborated that, "she's vaguely with it" (line 61). Prompted by the doctor's continuer at line 62 ("Mm"), the companion extended his response, "she knows she's gonna be sick and will sit up and lean over the bucket" (lines 63 to 64). This response did not appear to align with Adele's perception that she was not (usually, if at all) aware of vomiting during her attacks.

In extracts 6Di and 6Dii, persistent patient resistance to the doctor's questions appeared to result in the doctor turning to the companion for answers, and giving the companion 'the floor' to describe what he had seen. In this sense, the patient (and doctor) appeared significantly reliant on the companion to describe what he had witnessed.

In extract 6Diii below, Adele again resisted describing her seizure experiences (see lines 177 to 178) and this again resulted in the doctor 'giving the floor' to the companion to describe what he had seen (see lines 189 to 191).

Extract 6Diii.

- ((99 lines omitted))
165. D: And what happened in March?
166. P: ((Laughs)) Again, I'd been to London, I'm banned from
167. London aren't I? I'd been to London.
168. C: You had a, yeah, you had a very tiring weekend with
169. ((1 second)) (daughter's name).
170. P: I went for my daughter's birthday.
171. D: Mm.
172. P: Um, which obviously if you go to London that, if you're a
173. girl you do tend to do that, shopping.
174. D: Mm.
175. P: Shop till you drop, kind of thing. But it was quite a hectic
176. weekend, come back on the Sunday, and ((0.5 seconds))
177. again I can't really remember the details cos
178. I don't
(Patient turns to look at the companion)
179. C: You were in the bedroom and you, you passed out,
180. from what I remember.
181. P: I was in the bedroom ((0.5 seconds))
182. C: That's the first one I'd kind of experienced so I called
183. an ambulance straight away, cos again the signs were
184. she'd stopped breathing. Although again, back then,
185. there were no, there was no fitting or convulsions. It
186. was as if she'd, you know, stopped breathing, so.
187. P: Then they thought they'd found something with the heart
188. didn't they?
189. D: So what happened, so she stopped breathing and, and
190. she collapsed, and then what? How long did she lie
191. there for?

In the intervening talk between extract 6Dii and 6Diii, the patient discussed her time in intensive care following a seizure experienced in London. This talk primarily concerned the medical investigations and treatments undertaken during her stay. Adele also mentioned that she had experienced another seizure following her discharge from hospital in March (which again occurred in London).

At line 165 the doctor (who was facing the patient) asked, "And what happened in March?" However, in response Adele focused on the circumstantial and situational details of the seizure, "Again I'd been to London" (lines 166 and 167), "for my daughter's birthday" (line 170), "shopping" (line 173), "shop til you drop" (line 175).

Indeed, the first description of the patient's state leading up to the seizure in this dialogue (lines 165 to 177) came from Adele's companion, "had a very tiring weekend" (line 168); who was invited to contribute by the patient, "I'm banned from London aren't I?" (lines 166 to 167). Adele subsequently 'echoed' the companion's comment when she reported, "quite a hectic weekend" (lines 175 to 176).

After Adele had discussed the situational and circumstantial details of the attack (lines 170 to 175), she began to focus on the seizure itself, placing the seizure as having occurred on a Sunday, "come back on the Sunday" (line 176). However, Adele did not go on to discuss her experience, she instead reported an inability to remember what had happened, "and ((0.5 seconds)) again I can't really remember the details because I don't" (lines 177 to 178).

As previously discussed, Adele's use of "don't really" 'de-emphasised the boundary' (Paradis, 2003) between what she could and could not remember; the degree to which she 'remembered' was not presented as absolute. Nevertheless, her answer can still be seen as constituting a 'negative response' (Clayman, 2001). In addition, Adele only described the situational details and circumstances leading up to the seizure, and did not discuss (reported an inability to remember) details about the seizure itself. Stivers and Hayashi (2010) have observed that 'agenda transforming' answers include those where recipients focus on a particular aspect of the question and ignore another aspect.

Following her response, Adele's companion prompted Adele to continue with her description, "You were in the bedroom and you, you passed out, from what I remember" (lines 179 to 180). Adele may have prompted her companion's participation. During her prior talk, Adele turned to look at the companion (approximately at "details", line 177) before she cited an inability to remember what had happened (lines 177 to 178). Adele also said "don't" (line 178) rather slowly and did not complete her response. In response to her companion's prompt (lines 179 to 180), Adele responded by repeating a portion of it, "I was in the bedroom" (line 181), which was followed by a pause ("((0.5 seconds))"). It is possible that the companion considered this a sign of Adele experiencing difficulty providing a response. The companion subsequently offered a description of what he had witnessed (see lines 181 to 185).

After the companion had completed his description, (that ended with “so”, line 186), Adele described a possible seizure aetiology, “Then they thought they’d found something with the heart didn’t they?” (lines 187 to 188). Although this may have related to the doctor’s original question (“what happened in March?”, line 165), the patient’s response appeared to serve the function of transforming the topical agenda of the question; it focused on the possible cause (aetiology) and consequences of the seizure (subsequent medical investigation) rather than the seizure itself. Perhaps because of this, coupled with Adele’s prior resistance to the topical agenda of the doctor’s questions, Adele’s comment was completely (verbally) ignored by the doctor.

The doctor’s subsequent question was solely intended for the companion (evidenced by the pronoun “she”, lines 189 and 190), and did not make reference to Adele’s comment (lines 187 to 188), “So what happened, so she stopped breathing and, and she collapsed, and then what? How long did she lie there for?” (lines 189 to 191). Here, the companion was (again) ‘given the floor’ to describe what he had witnessed during that seizure episode.

Taken together, extracts 6Di, 6Dii and 6Diii demonstrate a case where the patient repeatedly resisted the topical agenda of the doctor’s questions and frequently reported an inability to remember what had happened during seizure events, often despite considerable prompting from the doctor. In the absence of a description of the patient’s seizure experiences, the doctor asked the companion to describe what he had witnessed. Consequently, significant reliance was placed on the companion to describe what he had seen.

2) The patient invited the companion

Patient resistance to the doctor’s questions was also observed in another type of companion involvement mechanism identified in the data. Akin to the organisational structure described above (extracts 6D), patients in the interactions described here frequently resisted describing what they had experienced during attacks, often despite considerable prompting from doctors to do so. Similarly, patients often resisted the ‘topical agenda’ (Stivers and Hayashi, 2010) of the doctor’s questions, and sometimes cited an inability to remember what they had experienced during attacks. Here too, many of their

responses were characterised as 'non-answer responses' (Stivers and Robinson, 2006) and 'negative responses' (Clayman, 2001).

However, unlike the companion involvement mechanism described previously, patient resistance in these interactions included frequently inviting or prompting their companion to provide answers to the doctor's questions, and to take 'the floor'. This type of response has been described as a 'strong negative response', and a show of 'overt resistance' (Clayman, 2001). In these interactions, the doctor gave the companion 'the floor' to describe what they had witnessed after the patient had repeatedly resisted discussing their experiences and had deferred to their companion to answer the doctor's questions. The doctor allowed the companion to describe what they had witnessed, by prompting them to continue, or by inviting them to clarify or elaborate on something they had said. This often meant that companions described what they had witnessed during an attack before the patient had described what they had experienced.

This type of companion involvement mechanism was observed in three of seven PNES patient consultations and just one of six epilepsy patient consultation (Colin's). As one might expect, significant reliance was placed on companions to describe what they had witnessed in these interactions.

An example of this organisational structure (and associated participant behaviours) is presented below in extract 6E. This extract is taken from Karen's consultation, a patient diagnosed with PNES.

The key moments in this extract take place at lines 185, 203 and 204 where Karen invites her companion to respond to the doctor's questions, and the companion begins to describe what he has witnessed. Following this, the doctor prompts the companion to continue with his description at line 209, giving the companion the floor to describe what he had seen.

Extract 6E.

184. D: OK. So how often are the blackouts happening now?
(Patient turns to look at the companion)
185. P: ((Laughs)) You'll have to answer that becau[se].
186. D: [You] know, the
the collapses [where you]
(Doctor turns to look at the companion)
187. C: [I reckon] er ((sighs)) she, at least once or twice
a day.
(Doctor turns to look at the patient)
188. D: So they've increased in frequency?
189. P: They are getting worse, yeah, as I told me GP about
190. that.
191. C: I, I reckon, I, I, it was twice, one or twice a day.
192. D: OK. And then you, you do have these other attacks as
193. well, so when did the other attacks start? ((1 second))
194. Blackouts started five years ago.
195. P: Um ((2 seconds)) the, the fit, the actually fitting side of
196. it?
197. D: Well you've mentioned attacks with seeing stars, you've
198. mentioned blank spells, you haven't talked about fitting
199. attacks yet. ((1 second)) What happened next, so you
200. had the, the blackouts where you collapsed?
201. P: They, then the fitting, then the fits started after that. Um
(Patient turns to face the companion)
202. ((1 second)) and how that come about, um ((3 seconds))
203. I, well ((3 seconds)) it were fitting after weren't it?
204. C: Right ((2 seconds)) I've noticed she'll blank out, I'll go
205. ((patient name)) ((patient name)) ((patient name)) and
206. then I know she's, she, she's going in, into some, some,
207. I don't know what you call it, I, I don't know what's wrong
208. with her, I'm not a doctor.
209. D: Mm.

The doctor first asked Karen, "So how often are the blackouts happening now?" (line 184). However, in response to the doctor's question, Karen demonstrated resistance by turning to look at her companion before beginning to speak, when she began with laughter (line 185). Haakana (2001, 2002) has shown that patients' sometimes use laughter outside of humorous discourse to perform 'delicate activities', and that the laughter can signify patient discomfort. The author has also observed that patients may deal with potentially problematic directives by laughing.

Following her laughter, Karen demonstrated 'overt resistance' (Clayman, 2001) to the topical agenda of the doctor's question, by directing her companion to answer on her behalf, "You'll have to answer that because" (line 185). Karen's account of her inability to answer was not completed ("because"). Nevertheless,

Karen's response can be seen as a 'non-answer response' (Stivers and Robinson, 2006) and as constituting a 'strong negative response' (Clayman, 2001); an attempt to answer the question was not made, an inability to respond was conveyed, and Karen deferred to her companion to respond on her behalf.

Before Karen could complete her account of why she was unable to provide an answer, the doctor began to clarify his question in an attempt to prompt her to respond, "You know, the collapses where you" (line 186). This was done in overlap with Karen's talk at line 185 (beginning near the end of "because"). The doctor's prompt began with, "You know" (line 186), this appeared to suggest that the doctor believed Karen had the capacity to answer. However, before the doctor completed his turn, the companion appeared to interrupt him. The companion began to respond to the patient's request in overlap with the doctor's talk (at "where", line 186), "I reckon er ((sighs)) she, at least once or twice a day" (line 187).

Returning to the patient (signalled by the doctor turning from the companion to face the patient, lines 187 to 188), the doctor then asked, "So they've increased in frequency?" (line 188). This question appeared to signal that (from the doctor's perspective) information previously given in the conversation about 'blackout' frequency (not shown above) suggested there had been an increase in "blackout" occurrence when compared to the information given by the companion at line 187.

However, the patient's response to the polar design (Raymond, 2003) of the doctor's question was not straightforward. Karen's 'expanded response' (Stivers and Heritage, 2001) began with, "They are getting worse" (line 189). It is not clear from the response whether Karen indicated that the frequency of her 'blackouts' had increased or whether the severity of her 'blackouts' had become worse. Karen was observed to say "yeah" (line 189) following her initial response, confirming the doctor's question. Nevertheless, given Karen's initial response, her answer remained somewhat ambiguous. Karen went onto qualify her response by describing how she knew her 'blackouts' had become "worse", "as I told me GP about that", (lines 189 to 190).

Perhaps in an attempt to help clarify the frequency of Karen's seizures, at line 191 the companion volunteered, "I, I reckon, I, I, it was twice, one or twice a

day". This remark mirrored his earlier response (at line 187). However, at line 191, the companion used the term "was", not making clear whether Karen's 'blackouts' had increased in frequency or not. In addition, the companion began his turns with, "I reckon" (lines 187 and 191). The use of "I reckon" suggested that the information the companion provided was from 'his opinion'; it also appeared to imply that he was not entirely certain of his answer(s).

However, the potential ambiguity of Karen's (and her companion's) responses was not addressed further in the conversation. The doctor's use of "OK" at the beginning of his next turn (line 192) marked a 'moment of topic transition' (Jefferson, 1981). The doctor turned his attention to the timeline of Karen's other seizure events, "And then you, you do have these other attacks as well, so when did the other attacks start?" (lines 192 to 193).

It was previously established (earlier in the consultation, not shown here) that Karen experienced different three types of seizures; one type involved 'dizzy spells' or 'blank spells' and 'seeing stars', the second, 'blackouts' or 'collapses', and another type of attack in which Karen 'blacked out' or 'collapsed' and 'fitted' or 'convulsed'. However, when the doctor tried to establish the timeline of Karen's other seizure events (at lines 192 to 193), he did not specify which type of attack he was asking the patient about, he used the term "other attacks" (line 192 and 193). Following a pause ("((1 second))", line 193), in which Karen could have, but did not respond, the doctor elaborated by adding, "Blackouts started five years ago", line 194). However, two different types of attacks still remained to be discussed in the consultation.

Karen's initial response of "Um" and a pause ("((1 second))") at line 195 suggested difficulty answering. Karen responded to the potentially problematic design of the question by asking the doctor to 'specify the terms' (Stivers and Hayashi, 2010). Karen asked the doctor to clarify which type of seizure he wanted to discuss, "the, the fit, the actually fitting side of it?" (lines 195 to 196).

In his response, the doctor's initial use of "well" (line 197) indicated that his answer was not going to be 'straightforward' (Schegloff and Lerner, 2009). The doctor went on to discuss the types of seizures Karen had already "mentioned" (line 197 and 198), "seeing stars" (line 197) and "blank spells" (line 198). After this, the doctor described what Karen had not yet discussed, "you haven't talked

about fitting attacks yet” (lines 198 to 199). In his ‘expanded response’ (Stivers and Heritage, 2001), the doctor confirmed Karen’s question, but gave a ‘non-conforming’ response to the ‘polar design’ (Raymond, 2003) of her question. The doctor also answered the question using a ‘round-about trajectory’ (Clayman, 2001). This may explain why a one second pause was observed following the doctor’s response (“((1 second))”, line 199), during which Karen could have begun to reply, but did not. Following this pause, the doctor asked, “What happened next, so you had the, the blackouts where you collapsed?” (lines 199 to 200).

In her response, Karen initially established that ‘the fits’ had started after the ‘blackouts’, “they, then the fitting, then the fits started after that” (line 201). In one sense, Karen’s response answered the doctor’s question, “what happened next” (line 199). However, the topical agenda of the doctor’s question was not straightforward. The doctor’s original question was, “when did the other attacks start?” (line 193) and he also discussed, “blackouts started five years ago” (line 194). These terms indicated a preferred response to include a measure of time, for example, how long Karen had experienced the fitting attacks for, or a date of onset. However, the topical agenda of the doctor’s question was ‘transformed’ to a degree in his later (‘clarifying’) talk, during which the doctor said, “you haven’t talked about” (line 198) and “what happened next?” (line 199).

Following this, Karen turned to face her companion and began to elaborate on her initial response, “um ((1 second)) and how that come about, um ((3 seconds)) I, well ((3 seconds))” (lines 201 to 203). Karen demonstrated difficulty constructing her response; it was punctuated by hesitation, including the use of “um” (lines 201 and 202) and pauses (including two three-second pauses at lines 202 and 203). It appeared that Karen was trying to describe both the timeline of events (line 201) and the details surrounding the onset of the attacks, “how that come about” (line 202), the latter of which may have been in response to the doctor’s use of, “you haven’t talked about” (at line 198).

However, instead of addressing the difficulty of her response (for example, by asking the doctor to clarify what he meant, as she had done previously), Karen dealt with the difficulty of responding by resisting to answer the question and deferring to her companion to respond, “it were fitting after weren’t it?” (line 203). Karen’s response also appeared to suggest that she was uncertain of her

earlier answer (“then the fitting, then the fits started after that”, line 201).

In response, the companion ignored the topical agenda of Karen’s question (the timeline of ‘fitting’ events). The companion began his description with “Right” (line 204), which has been recognised as a discourse marker (Stokoe, 2000). He then went on to describe what he typically witnessed during the onset of one of Karen’s (‘fitting’) seizures (lines 204 to 208). The companion was officially given the floor to describe what he has witnessed when the doctor prompted him to continue with his description at line 209 (“Mm”).

Karen’s consultation was characterised by her resistance to the doctor’s questions. Karen repeatedly resisted answering the doctor’s questions, often despite prompting from the doctor to do so, and invited and prompted her companion to answer. When she deferred to her companion, Karen sometimes provided ‘non-answer responses’ (Stivers and Robinson, 2006). These actions suggested that she was unable to remember or report what she had experienced. In the absence of an answer, deferring to another person to respond has been described as a ‘strong negative response’ and a show of ‘overt resistance’ (Clayman, 2001).

After Karen repeatedly displayed resistance, and invited and prompted her companion to respond, the doctor gave the companion the floor to describe what he had witnessed. Consequently, significant reliance was placed on the companion to describe what he had seen in this interaction.

3) The companion self-initiated

In a number of interactions, companions persistently self-initiated and intervened in patients accounts to the extent that they eventually ‘gained the floor’ to describe what they had witnessed (often before the patient had the chance to describe their experiences). A lot of this self-initiated companion talk was characterised as ‘extensive departures’ (Stivers and Heritage, 2001) from the topical agenda of the discussion, and constituted what Stivers and Heritage (2001) have termed ‘narrative expansions’. In addition to self-initiating, companions in these interactions often interrupted the patient’s talk, and sometimes responded to questions intended for the patient.

Companions eventually gained the floor in these interactions after the patient prompted the companion to continue with their description, or asked them to clarify or elaborate on something they had said. Doctors were sometimes observed to intervene in these companion accounts, and to try to redirect the conversation back to the patient. However, this technique did not always work, and the companion often continued to intervene and dominate the conversation. In other instances, the doctor did not appear to try to redirect the conversation in the patient's favour until after the companion had 'conceded' or 'relinquished' 'the floor' (as demonstrated in the extract below).

Persistent companion intervention was observed on a number of occasions across three PNES patient consultations, but did not feature in any of the epilepsy patient consultations analysed. In contrast to the other interactive mechanisms described, the reliance placed on companions to describe what they had witnessed in these exchanges was difficult to assess. Similarly, patient resistance to the doctor's questions was difficult to determine. In one of the three consultations (Peter's), the companion intervened to such an extent that Peter's resistance to the doctor's questions and the reliance placed on his companion to describe what she had seen could not be adequately assessed.

An example of this companion involvement mechanism (and associated participant behaviours) is presented below in extracts 6F. Due to its length, the extract is presented and discussed in two sections. The extracts were taken from Peter's consultation, a patient diagnosed with PNES.

Key moments in extract 6Fi take place at line 24, where the companion self-initiates her involvement in the conversation, at lines 26 to 29 and lines 31 to 34, where the companion describes what she had witnessed, and at lines 30 and 35, where the doctor prompts the companion to continue with her description.

Extract 6Fi

17. D: So what can you tell me about the first attack?
18. P: Er, we got up, the kids were opening their presents
19. ((0.5 seconds)) and er we had breakfast, I washed the
20. pots.
21. D: Mm hmm.
22. P: And I just went in the room and I felt, just had this
23. feeling and I just dropped on the sofa.
24. C: No, you were putting pots in the dishwasher.
25. P: Dishwasher, um
26. C: And you come in and said "Oh I feel a bit funny." I said
27. "Have you been getting up and down, like putting
28. things in the dishwasher?" Cos obviously sometimes if
29. you stand up too fast it can make you dizzy.
30. D: Mm.
31. C: Um, he said "not really" and then just dropped and we
32. had to, he just laid there, luckily enough he was near
33. the pouffe, and he fell onto the pouffe and just laid
34. there. Um, we called an ambulance.
35. D: Mm.

In this extract, the doctor asked Peter, "So what can you tell me about the first attack?" (line 17). In response, Peter described the situational and circumstantial details of his first attack, "we got up, the kids were opening their presents ((0.5 seconds)) and er we had breakfast," (lines 18 to 19). It was established earlier in the consultation that Peter experienced his first attack on Christmas day, hence his mention of "presents". During his response, Peter said "er" twice (line 18 and 19) and a 0.5 second pause was observed (line 19), which indicated that Peter had some difficulty describing the circumstances of the seizure. Peter's account concluded with, "I washed the pots" (line 19 to 20). Following this, the doctor prompted Peter to continue with his description, "Mm hmm" (line 21).

In response, Peter appeared to begin to turn his attention to what could be considered the 'other' topical focus of the doctor's question, what he had experienced. Peter began by elaborating on the situational details of the event, "and I just went in the room" (line 22). However, following this, Peter showed resistance describing the details of the attack. Peter began to describe how he felt immediately before the event, "and I felt" (line 22). However, Peter did not offer a description of this 'feeling'. Instead, Peter reformulated what he was going to say to, "just had this feeling" (lines 22 to 23). The 'feeling' itself was not described. Peter then recounted what he remembered before losing consciousness, however, only scant detail was given, "and I just dropped on the

sofa" (line 23).

Following his description, Peter's companion self-initiated talk that disagreed with his account. The companion's account began with, "No" (line 24), and in the account that followed, she disagreed with the circumstances of the event and the 'terms' that Peter had used to describe the situational details of the event. For example, "washed the pots" (lines 19 to 20) was specified by the companion as "dishwasher" (line 24, 25 and 28) and "sofa" (line 23) was specified by the companion as "pouffe" (line 33).

After she had said, "No" (line 24), the companion went on to say, "you were putting pots in the dishwasher" (line 24). Peter confirmed his companion's account with a partial repetition, "Dishwasher", followed by "um" (line 25). It may have been the case that Peter was going to say more, 'um' has been recognised as 'signifying a delay' in speaking and as indicating that 'more conversation is to follow' (Clark and Fox Tree, 2000). However, only a momentary pause was observed between Peter's use of "um" and his companion resuming her account.

In her elaboration, the companion added a little more detail about the event, "And you come in and said "Oh I feel a bit funny"" (line 26). Her reported speech indicated that the feeling to which Peter had alluded earlier was not a feeling he normally experienced, it was 'out of the ordinary', "a bit funny". The use of "Oh" at the beginning of the reported speech also appeared to indicate that Peter was (possibly) 'surprised' or 'suddenly aware' of the feeling experienced. It may have also been used as a device to 'add emphasis' or 'get attention' (Aijmer, 1987).

Following this, the companion described her response to Peter's reported speech, "I said "Have you been getting up and down, like putting things in the dishwasher?"" (lines 26 to 28). This description may help to explain why the companion was not satisfied with Peter's description of "washed the pots" (lines 19 to 20), which the companion subsequently disagreed with at line 24 ("No, you were putting pots in the dishwasher"). In the companion's subsequent talk the action of "putting the pots in the dishwasher" was linked with the feeling (subjective symptom) Peter (potentially) experienced, "Cos obviously sometimes if you stand up too fast it can make you dizzy" (lines 28 to 29). At

this point, the doctor's use of the continuator, "Mm" (line 30) prompted the companion to continue with her description, and the companion was given 'the floor' to continue with her account.

The use of "um" (line 31) at the start of the companion's following turn appeared to indicate that 'more talk was to follow' (Clark and Fox Tree, 2000). The companion continued with her description by reporting that Peter responded, "not really" (line 31). Peter's (reported) response may have reflected the companion's (reported) question, which on one level questioned the act of "getting up and down" (line 27) and on another level implied that this had caused him to feel "dizzy" (line 29). Peter's (reported) response of "not really" (line 31) did not appear to disagree with the companion's question per se, he having done the activity (note Peter's repetition of "dishwasher" at line 25), but rather the implied consequences of the activity, that it had made him feel "dizzy". Therefore, the companion's initial assumption that Peter's "funny" (line 26) feeling was associated with 'dizziness' following "getting up and down" (line 27) (evidenced in part by the companion's use of "obviously", line 28) was not (necessarily) proved correct.

Following this, the companion repeated Peter's description of what had happened ("just dropped", line 23) in her account, "then just dropped" (line 31); she also twice reported that Peter had, "just laid there" (line 32 and lines 33 to 34). The companion then went on to add a little more situational detail to her account, reporting that Peter had, "fell onto the pouffe" (line 33). Finally, the companion said "Um, we called an ambulance" (line 34). Following this, the doctor (again) prompted the companion to continue with her account ("Mm", line 35).

The extract above shows that the companion self-initiated to become involved in the conversation to describe what she had seen. The patient demonstrated some resistance to describing his experience, for example, his reformulation of "I felt" to "just had this feeling" (at lines 22 to 23). However, Peter's resistance to the doctor's questions and his reliance on his companion to describe what she had witnessed was difficult to assess because of her self-initiated talk. For example, it is not known whether Peter would have continued to describe his attack (for example at line 24) or would have elaborated on his description (for example at line 25) had his companion not intervened.

Following line 35, the companion went on to discuss the consequences of the attack, the details of Peter's subsequent hospital stay, the medical investigations undertaken, and Peter's current medications. The extract shown below (6Fii) contains the concluding part of that talk.

Key moments in extract 6Fii take place at line 69, where the doctor prompted the companion to continue, and at line 70, where the companion 'conceded the floor'. Key moments also occur at line 74, where the companion interrupted the patient, at line 93, where the companion began to describe what she had witnessed. Other important moments occurred at line 96, where the doctor prompted the companion to continue with her description, and at lines 105 to 106, where the doctor asked the companion to elaborate on something she had mentioned.

Extract 6Fii.

66. C: To see if it has any effect. She said that she thinks
67. from er, some of the ((0.5 seconds)) symptoms it could
68. possibly be related to seizures or epilepsy.
69. D: Mm.
70. C: ((2 seconds)) And that's as much (as) we really know.
(Doctor turns his head to face the patient)
71. D: ((1 second)) So how often were they happening at
72. first?
73. P: Had that one Christmas Day, we [got]
(Patient turns to face the companion, and reaches toward her
handbag, which is placed on her lap)
74. C: [I've] got me diary ((laughs)) I have been trying to keep
75. a record. Um, there were Christmas Day, then it
76. happened about three or four weeks later.
77. D: Mm hmm.
((13 lines omitted))
91. C: Went several days and then had another two in a three
92. day period. Um, last week he had one on Monday and
93. one on Wednesday. But after he's having one of these
94. episodes where he, I can see him going, his face, from
95. the outside his face relaxes.
96. D: Mm.
97. C: Um, and he looks vacant, and I'll say "Are you going to
98. go?" And he says "Yeah." And we try and get him sat
99. somewhere quick as possible, and then he just goes all
100. floppy. Sometimes ((laughs)) (()) sometimes he's
101. responsive enough to answer me when I talk to him
102. and sometimes he's not. Um, he'll go to sleep and he
103. can stay that way anything between an hour and four
104. hours maximum.
105. D: When you say sometimes he can answer, how does he
106. answer?
107. C: Very, you'll "((Patient name, patient name))." And he's
108. like "Uh." "((Patient name))?" "Yes." So it takes a bit of
109. prompting to get an answer from him.

The patient had not spoken in the consultation since line 25 (in extract 6Fi), and did not speak again until line 73 in the extract above. Before Peter re-entered the conversation, it was notable that the companion did not lose the floor (for example, by the doctor redirecting his attention to the patient), but rather she 'conceded' the floor. At line 69 the doctor prompted the companion to continue with her description ("Mm"). However, there was a two second pause at the beginning of the companion's following turn (line 70), indicating that she was hesitant. In addition, the talk that followed suggested the companion had already completed what she had to say (at line 68), "And that's as much (as) we really know" (line 70). Her use of "really" here appeared to be a 'truth-attester' (Paradis, 2003). "Really" was positioned before "know"; the companion had

explained all that was 'really known' about Peter's condition with reference to medical investigations and possible diagnosis.

After the companion had conceded the floor, the doctor turned back to face the patient, and following a one second pause asked, "So how often were they happening at first?" (lines 71 to 72). In response, Peter did not appear to resist the doctor's question. He initially responded with "Had that one Christmas Day" (line 73), which had been established earlier in the conversation as the date of the first seizure he had experienced. Peter then began to elaborate on his initial response, "we got" (line 73), and turned to face the companion when he said this, reaching towards his companion's handbag as he did so, which was placed on her lap. However, at this point his companion interrupted Peter's talk. This was evident as the patient's turn was not completed and the companion began to speak in overlap with the patient's talk (at "got", line 73). His companion added, "I've got me diary ((laughs)) I have been trying to keep a record" (lines 74 to 75).

Despite Peter having indicated that "we got" (presumably with reference to the diary record), the companion used the term, "I've got me diary" (line 74). Following some laughter, the companion then said, "I have been trying to keep a record" (lines 74 to 75). The use of "I have" suggested that the companion alone, as opposed to both Peter and herself, had been "trying to keep a record" of Peter's seizures. It may have also been used to convey that the companion had an 'epistemic privilege' (Heritage, 2012) to relay the information.

Thereafter, the companion gave an extensive account (some of which is detailed in the extract shown) of the dates and times of Peter's seizures, from the one experienced on "Christmas Day" (line 75) to the most recent seizure Peter had experienced ("one on Wednesday", line 93) – an account to which Peter did not contribute.

At line 93, a shift in the topical agenda of the companion's talk was observed. Initially the companion was observed to say, "But after he's having one of these episodes where he," (lines 93 to 94). This suggested that the companion was going to discuss Peter's state "after" he had experienced an "episode". However, the companion reformulated her statement and discussed Peter's state before a seizure experience, "I can see him going" (line 94) and ""Are you

going to go?” (line 97). The companion’s reformulation appeared to indicate that, instead of first (or only) commenting on Peter’s state after a seizure, that she felt comfortable starting her description from the ‘beginning’, and discussing Peter’s pre-ictal symptoms. The reformulation might have also indicated that the companion intended to give an expansive account of what she had witnessed; which she went on to do.

At line 96 the doctor prompted the companion to continue with her account (“Mm”), and in doing so gave the companion ‘the floor’ to describe what she had witnessed. In the account that followed, the companion discussed how Peter typically looked before an attack (“his face relaxes”, line 95 and “looks vacant”, line 97), his responsiveness before an attack (“And he says “Yeah””, line 98), his physical state during an attack (“he just goes all floppy”, lines 99 to 100), his responsiveness during an attack (“sometimes he’s responsive enough to answer”, lines 100 to 101), his state following an attack (“he’ll go to sleep”, line 102) and his return to ‘normality’ (“between an hour and four hours maximum”, lines 103 to 104).

The doctor’s question to the companion at lines 105 to 106 (“When you say sometimes he can answer, how does he answer?”) signalled that the companion had ‘retained the floor’. In response to the doctor’s question, the companion reported how she had prompted the companion to respond during attacks (lines 107 to 109).

In the extract presented above (and extract 6Fi shown earlier) Peter’s companion repeatedly intervened in his accounts, including intervening in his account (line 74) with lengthy and detailed versions of her own, thereby contributing more than Peter, both verbally and in terms of the information given.

With reference to the doctor’s questions, the companion gave ‘extended answers’ (Stivers and Heritage, 2001) that often ‘transformed the topical agenda’ (Stivers and Hayashi, 2010) of the doctor’s questions. This was done with reference to the doctor’s question at line 17, “So what can you tell me about the first attack?” Not only did the companion disagree with the patient’s account and offer her own version of events (lines 24 to 34), she expanded on her answer and discussed calling for an ambulance (line 34), Peter’s hospital

stay, his medical investigations and medications (not shown in extracts), and possible diagnosis (line 68). In response to the doctor's question at lines 71 to 72, "So how often were they happening at first", the companion interrupted the patient and proceeded to date every seizure that Peter had experienced from the first seizure ("Christmas Day", line 75) to his most recent ("one on Wednesday", line 93). The companion then 'shifted topic' at line 93 and gave a lengthy description of what she had witnessed during one of Peter's attacks. 'Extensive departures' (Stivers and Heritage, 2001) were made from the topical agenda of the questions the doctor had directed to the patient.

Stivers and Heritage (2001) have labelled 'extensive departures' from the agenda as 'narrative expansions'. The authors have observed that 'narrative expansions' are one way that patients (and others) can introduce their own agenda of concerns. In the case presented here, the companion appeared to use 'narrative expansions' to introduce her own agenda of concerns, what she thought the doctor should know about Peter's attacks (this included information about medical investigations and a potential diagnosis).

The companion in this interaction described what she had witnessed before the patient had described his experiences. Peter's resistance to the doctor's questions could not be adequately assessed due to the companion repeatedly intervening in the patient's talk. The patient was not given the space or time necessary to demonstrate being resistant or not. Similarly, the patient's reliance on the companion to describe what they had witnessed could not be adequately assessed.

3.4 Subjective seizure symptoms

All companions in the data reported or stimulated discussion of at least one (frequently a handful, and sometimes several) of the patients' subjective seizure symptoms.

When they described subjective seizure symptoms, companions often discussed what patients had told them about what they had felt or thought during attacks, and typically reported the patient's speech when they did this (as in extract 6G). Companions also described the patients' subjective state and symptoms from their own observations of attacks (as in extract 6H). However,

without these types of knowledge, companions in the data struggled to provide information about patients' subjective seizure symptoms (as seen in extracts 6G and 6K).

There were numerous instances in the data where companions reported a subjective seizure symptom before the patient had mentioned or discussed the symptom. Some companions did this after they were asked by the doctor (or occasionally the patient) to describe what they had witnessed during attacks (for example, as in extracts 6G and 6H). Other companions described or stimulated discussion of the patients' subjective seizure symptoms by self-initiating and intervening in the patient's account, and sometimes interrupted the patient to do this (for example, as in extracts 6I and 6J). In these instances, the doctor was typically observed to ask the patient to confirm and elaborate on a symptom described by the companion (for example, as in extract 6G). However, in a number of cases, a subsequent description of the symptom from the patient was either not attempted or achieved (for example, as in extract 6H).

On other occasions, companion descriptions of what they had witnessed stimulated discussion of the patients' subjective seizure symptoms. In their descriptions of what they had witnessed, companions often alluded to the patients' subjective state (for example, as in extract 6I), as a consequence of which patients sometimes introduced a subjective symptom into the discussion. In other instances, the doctor asked the patient (less so, the companion) to confirm if they had experienced and/or prompted the patient to discuss a subjective seizure symptom not previously (explicitly) mentioned in the conversation (as seen in extract 6I).

When patients were stimulated or prompted to describe a subjective seizure symptom not previously discussed, they often described the symptom using similar examples and contexts as the companion (as seen in extract 6G). They also frequently repeated terms previously used by the companion (as seen in extracts 6H and 6I) or the doctor (as seen in extract 6I) to describe the symptom.

These features are illustrated in the extracts presented below.

Extract 6G below shows a companion who introduced a subjective seizure symptom not previously mentioned by the patient into the conversation. It is not known whether the patient would have discussed this symptom ("déjà vu") in

the companion's absence. The companion discussed the symptom in some detail. However, it appeared that she was not able to describe what Arthur experienced as "déjà vu" beyond naming the symptom, describing what she had witnessed during one of the events, and describing what the symptom meant. It appeared that this information was within the patient's epistemic domain. After the companion had described the symptom of "déjà vu", the doctor asked the patient to describe what he had experienced. However, the patient seemed to find describing what was meant difficult. Subsequently, the companion confirmed that what the doctor had described was what Arthur experienced as "déjà vu".

The extract is taken from Arthur's consultation, a gentleman with epilepsy.

Extract 6G.

81. C: Yeah, but then other times he can have little do's and then.
82. D: What, what happens in those?
83. C: Er ((1 second)) it's just, like you say, it's like a déjà vu it's like,
84. don't you?
(Patient turns towards the companion)
85. P: Mm, yeah.
(Patient turns back towards the doctor)
86. C: It's, he can, he can be looking at something, he'll watch it and
87. then he'll just go and he'll, he'll go red again and then it'll just
88. go off, he'll just take some, a few deep breaths and then
89. come round and he says "Ooh I've just had one of them
90. funny" funny little do's he calls it.
91. D: Do you experience, I mean what, what do you mean by déjà
92. vu?
93. P: ((2 seconds)) Er ((1 second)) I mean it, er every time it comes
94. it's the same thing ((1 second)) so.
95. D: So it's the same feeling each time or, or, déjà vu means that
96. you feel that you've done this before.
97. P: Mm hmm.
98. D: So you come into this room and although, oh I don't know,
99. you've probably never been here before, you feel like you've
100. been here before, it's that sort of feeling ((1 second)) is that
101. what you experience?
102. P: Yeah, when, when I'm at home like, you know.
103. C: He could be watching something or we can be out somewhere
104. ((2 seconds)) and he, he says "Ooh I've got that feeling of
105. déjà vu, as if I've been here before."
106. D: Yes ((1 second)) OK.

Prior to excerpt shown above, Arthur's companion had (briefly) discussed what she had witnessed during one of Arthur's 'fitting' seizures. At line 81, the companion described a different type of event that Arthur experienced, "other

times he can have little do's". Following this, the doctor asked the companion to elaborate, "What, what happens in those?" (line 82).

In her initial response, the companion initially hesitated ("Er (1 second)") before she said, "it's just" (line 83), this indicated that the companion found responding to the doctor's question difficult. Following this, the companion reformulated her response. She turned to look at Arthur and said, "like you say" (line 83), and then went on to describe, "it's like a déjà vu it's like" (line 83). Here, the companion introduced a subjective seizure symptom that had not been previously discussed in the consultation, "déjà vu". She also reported that she knew about this because Arthur had told her, "like you say" (line 83). However, the companion also indicated she was not entirely certain of her description. In her account, the term "déjà vu" was 'sandwiched' by, "it's like" (line 83). She then prompted Arthur to confirm (and possibly elaborate on) her description, "don't you?" (line 84). However, Arthur offered minimal confirmation in return, "Mm, yeah" (line 85).

Following this, the companion elaborated on her initial description, giving an example of the circumstances of one of Arthur's "little do's" (line 81 and 90), "It's, he can, he can be looking at something, he'll watch it" (line 86). She then discussed changes in Arthur's behavior and physical state, "and then he'll just go and he'll, he'll go red again" (lines 86 to 87). She also described Arthur's return to normality, "and then it'll just go off, he'll just take some, a few deep breaths and then come round" (lines 87 to 88). Following this she reported Arthur's speech, "and he says "Ooh I've just had one of them funny" funny little do's he calls it" (lines 89 to 90). However, the companion did not expand on her description of "déjà vu" per se, that is, what Arthur had experienced as "déjà vu". This may have been because the companion did not have access to this 'privileged' information.

In the turn that followed, the doctor questioned Arthur about his "déjà vu" symptoms. The doctor began his question with, "Do you experience" (line 91), however, he reformulated this to, "I mean what, what do you mean by déjà vu?" (line 91 to 92). Arthur demonstrated some difficulty constructing a response, "(2 seconds) Er (1 second)" (line 93). However, Arthur did go on to describe what he 'meant', "I mean it, er every time it comes it's the same thing (1 second) so" (lines 93 to 94). Here too, Arthur appeared to find describing his experience

difficult. Arthur concluded his response with a pause, “(1 second)” and ended it with, “so” (line 94) (without being interrupted by the next speaker). Schiffrin (1987) has reported that the use of ‘so’ at the end of a turn can signal that the speaker wants to relinquish the floor.

As demonstrated by the doctor’s response, Arthur’s description of “*déjà vu*” was treated as ambiguous and requiring clarification. The doctor asked Arthur, “So it’s the same feeling each time or, or, *déjà vu* means that you feel that you’ve done this before” (lines 95 to 96). However, Arthur only responded to the doctor’s question with minimal confirmation, “Mm hmm” (line 97). This may have been done in response to the ‘polar design’ (Raymond, 2003) of the doctor’s initial question, “So it’s the same feeling each time” (line 95). However, the doctor’s subsequent talk, “or, or, *déjà vu* means that you feel that you’ve done this before” (lines 95 to 96), opened up other possibilities of patient response, and suggested a more expansive answer was preferred.

Following this, the doctor gave Arthur an example of what he understood “*déjà vu*” to be, “So you come into this room” (line 98), “you feel like you’ve been here before, it’s that sort of feeling” (lines 99 to 100). Following a one second pause, the doctor then questioned, “is that what you experience?” (lines 100 to 101). In his initial response, Arthur confirmed the doctor’s question, “Yeah” (line 102). However, instead of describing the sensation of “*déjà vu*” experienced, Arthur described a situational detail of his experience, “when, when I’m at home like, you know” (line 102).

It is notable that while the doctor’s example was set in the examination room, the example given by the patient was set in his home. Possibly sensing the difficulty that had occurred in the conversation, the companion self-initiated at line 103 to add, “He could be watching something or we can be out somewhere”. Here the “watching” was contrasted to being “out somewhere”; indicating the “watching” example given earlier by the companion (at line 86) had occurred at their home, and that her prior description had potentially influenced Arthur’s subsequent response (at line 102).

After this, the companion paused for two seconds before reporting Arthur’s speech, “and he, he says “Ooh I’ve got that feeling of *déjà vu*, as if I’ve been here before.”” (lines 104 to 105). In doing so, the companion repeated the terms

of the doctor's question, "been here before" (line 100), and confirmed that this was the sensation Arthur experienced.

In extract 6H presented below, the presence of a companion appears to limit opportunities for the patient to describe how she had felt or what she had thought when she regained consciousness after an attack. The companion provides a description of Mary's subjective state during and following a seizure event from his own observations. This is the first time these symptoms had been discussed in the consultation (Mary had discussed some subjective seizure descriptions earlier in the consultation (not shown) when describing her seizure triggers and what she had experienced immediately before a seizure event). Following on from the companion's description, the doctor directs the patient to describe how she felt after an event. However, the patient's account is focused on how she typically feels later in the evening. It appears that Mary's subjective account 'left off' from where her companion's account ended. In addition, Mary repeats some of the terms previously used by her companion to describe her subjective state; this suggests that the companion's account had influenced the patient's.

Extract 6H

134. C: Then she just passes out and really, does really like
135. slow breathing but really heavy breathing like
136. (Breathes in/breathes out hard)
137. D: Yeah.
138. C: Like that, really, really out of it, about two minutes, then
138. she wakes up and she's oh like ((1 second)) and
139. hasn't got a clue where she is. ((laughs))
140. D: And how long does that section go on for?
141. C: This lasts about, see it takes about five minutes after
142. that to come round. Oh it takes about ten minutes
143. altogether before she's like really knows where she is
144. and what's happened.
145. D: And then what, what do you feel like then?
146. P: I just, just feel like I can't remember anything what I've
147. done that day, well what I've eaten, it takes me till
148. whole of that night um to really come round and
149. remember things.

The extract above follows on from extract 6A, presented earlier in the chapter. Here the companion began to describe what he had witnessed towards the end of one of Mary's seizures. Following on from his description of Mary's breathing, "slow breathing but really heavy breathing" (line 135) and demonstration of this

("[breathes in/breathes out hard]", line 136), the companion discussed that Mary was, "really, really out of it" (line 138), at which point the companion began to describe subjective seizure symptoms not previously discussed by the patient earlier in the consultation.

In his account, the companion's description of "out of it" (line 138) indicated that Mary was not in her normal state of mind. His use of "really, really" (line 138) 'intensified' (Paradis, 2003) the degree to which Mary was "out of it". It appeared to indicate that Mary was unconscious and/or had significantly reduced consciousness, which was made evident in the companion's following talk, "then she wakes up" (lines 138 to 139). Continuing with his description of Mary's return to normality, the companion described that when Mary initially regained consciousness that she, "hasn't got a clue where she is" (line 139).

Following this, the doctor asked the companion to specify how long Mary remained in that state, "And how long does that section go on for?" (line 140). In response, the companion described the different grades of consciousness and awareness he had witnessed. He first described, "see it takes about five minutes after that to come round" (lines 141 to 142); the companion's description of "that" (line 142) referred to Mary's initial return to consciousness, described by the companion at line 138, "wakes up". The companion's use of "come round" indicated a gradual return to normality. He later described that, "it takes about ten minutes altogether before she's like really knows where she is and what's happened" (lines 142 to 144). The companion's descriptions of Mary's subjective state suggested that she initially lacked knowledge, understanding or awareness of her surroundings, where she was ("where she is", lines 139 and 143) and what had happened ("What's happened", line 144) before she regained full awareness ("really knows where she is", line 143).

The companion's descriptions of Mary's subjective symptoms appeared to be based on his observations of Mary's state. It appears likely that the companion evaluated Mary's state during this time by her level of responsiveness (how he knew she was "out of it", line 138, didn't "have a clue", line 139, had "come round", line 142, and had regained awareness, "really knows", line 143). However, her companion (unlike the companion in extract 6H) did not report Mary's speech, or what she had told him about her experiences. Nevertheless, he still provided a description in which he conveyed Mary's subjective state.

Mary had not previously described what she had thought or felt during the experiences described by the companion. However, subsequent opportunities for Mary to discuss these appeared limited. The doctor may have found the companion's descriptions of Mary's subjective state during that time sufficient, or concluded from the description that Mary would not be able to contribute anything. Following the companion's account, the doctor returned to the patient and asked, "And then what, what do you feel like then?" (line 145). Here, the doctor did ask Mary to discuss her subjective seizure symptoms. However, the design of the doctor's question appeared to be directed towards the symptoms Mary experienced after regaining awareness/consciousness, "then?" (line 145).

In response, Mary's subjective account 'left off' from where her companion's account had ended. Mary reported that, "I just, just feel like I can't remember anything" (line 146). Mary did go onto to elaborate the types of things she could not remember after an event, "what I've done that day, well what I've eaten" (lines 146 to 147). However, Mary's description was focused on the subjective seizure symptoms she experienced later in the evening, following an attack, "it takes me till whole of that night um to really come round and remember things" (lines 147 to 149).

The subjective symptoms Mary reported may also have been influenced by her companion's descriptions. Mary's description of 'remembering' ("remember", lines 146 and 149), may have been influenced by the companion's account, for example, "really knows ...[]... what's happened" (lines 143 to 144). Similarly, Mary's description of "really come round" (line 148) may have been influenced by the companion's prior use of "come round" (line 142).

In extract 6I below, the companion frequently self-initiates to describe what he has witnessed; at times this includes interrupting the patient. The companion's descriptions potentially influence the subjective seizure symptoms subsequently reported by the patient. This appears to be an indirect consequence of the companion's descriptions. The companion typically describes what he had observed without explicitly reporting the patient's subjective symptoms. However, his descriptions appear to influence the direction of the doctor's questions to the patient. Following on from the companion's descriptions, the doctor repeatedly asks the patient to confirm the presence of subjective seizure

symptoms not previously (explicitly) mentioned in the conversation. In addition, the patient sometimes describes subjective symptoms using terms previously used by the companion, and the doctor. The companion's contributions and the doctor's questions appear to influence the patient's descriptions of their subjective symptoms.

Extract 6I.

48. D: Mm. Can you remember how they first started?
49. P: I just don't feel right, I just don't feel meself, I feel ((2 seconds))
50. a bit light-headed. How can I explain? I
51. don't, a bit, a bit light-headed, don't, just don't feel right
52. in meself.
53. D: Mm hmm.
54. P: And ((1 second))
55. C: And, you know, I, I can usually tell when
56. it's starting because she starts to slur her words.
57. D: What before, you can tell?
58. C: I can tell.
59. P: He can, aye.
60. C: I can tell when they're coming on cos she'll, like her
61. talking starts to get a bit laboured and a bit slurred.
62. D: Mm.
63. C: And she'll end up asking for an, an inhaler or
64. something like that even if she doesn't need it
65. ((1 second)) do you know what I mean? She'll say "Oh
66. well I need me inhaler, I need me inhaler" or
67. P: Like breathing in't it?
68. C: ((mh))
69. D: So what, what do you notice then? You, you feel not
70. right. Do you feel short of breath or?
71. P: ((1 second)) Yeah.
72. D: Mm hmm.
73. P: I do, I, I do, I feel short of breath, but I don't know if it's
74. cos I'm panicking like, I panic, cos I do have panic
75. attacks anyway.
76. D: Mm.
77. P: I don't know if it's because I've had a, they're coming
78. on that short ((2 seconds)) oh how can I explain it?
79. They come on that quick I'm thinking oh God, is this it?
80. I know it sounds awful but ((1 second)) when I'm on
81. me own, I mean last time I were quite, quite lucky
82. weren't I?
83. C: Mm.
84. P: Because I only had to press my button once, because I
85. had a really bad do then, a really bad do, um, er, if
86. nobody had been there well I'd have swallowed me
87. tongue and that'd have been it like. So ((1 second)) I
88. think it's cos I panic when I know I don't feel right, you
89. know.
90. D: Mm.

91. P: I start labouring more because I panic cos I know
 92. they're happening, if you know what I mean, I just go
 93. light-headed a little bit mainly, that's (it).
 94. C: She always seems to ask for a flannel as well "I need a
 95. flannel, I need a flannel."
 96. D: Do you feel hot?
 97. P: Yes.
 98. C: Yeah, so
 99. P: Really hot.
 100. D: Does your heart seem to race?
 101. P: Oh God yeah ((laughs)) I can feel that.
 102. D: ((5 seconds)) And how long does this go on for,
 103. this feeling?
 104. P: Quite a few minutes, about three minutes ((1 second))
 105. it's not much time.

In the extract presented above, the doctor asked Alison, "Mm. Can you remember how they first started?" (line 48). This occurred early on in the consultation, and was the first time the doctor had asked Alison to describe her experiences. The doctor asked Alison, "how they first started" (line 48), which appeared to indicate that he wanted Alison to discuss the circumstances surrounding the onset of her seizures. However, in response, Alison described what she typically experienced during the beginning of a seizure episode.

In her response, Alison discussed some subjective symptoms: "I just don't feel right, I just don't feel meself" (line 49). As Jacobs (2010) has reported, the speaker is both the subject ('I') and the object ('meself') of the phrase 'I don't feel meself', and use of the phrase suggests that there is a 'self' that is normally experienced, which is unlike the one described - expressed in Alison's initial response, "I just don't feel right". However, despite an indication that Alison experienced something other than a normal state, Alison's description focused on what she did not feel, as signalled by her repetition of, "I just don't" (lines 49 and 51).

In her response, Alison offered another subjective seizure symptom, "a bit light-headed" (line 50). This was preceded by hesitation (a two second pause, line 49) and was followed by a literal expression of the difficulty Alison faced describing how she had felt, "How can I explain?" (line 50). Brouwer (2003) has called these types of questions to the 'self', 'word search markers' and has suggested that they perform two functions; they signal that the speaker finds the talk problematic and they invite hearers to help. Alison proceeded with her

account, though repeating what she had previously described, “I don’t, a bit, a bit light-headed, don’t, just don’t feel right in meself” (lines 50 to 52).

Following a prompt by the doctor to continue (“Mm hmm”, line 53), it appeared that Alison was going to elaborate on her prior description, beginning with “And” (line 54). However, after the one second pause that followed, Alison’s companion self-initiated to describe what he had witnessed. The companion described that he had witnessed Alison’s state during the onset of her seizure episodes, and could identify the start of these from his observations, “And, you know, I, I can usually tell when it’s starting because she starts to slur her words” (lines 55 to 56). Prompted by the doctor to continue with his description, “What before, you can tell?” (line 57), and subsequent confirmation by the patient, “He can, aye” (line 60), the companion described that Alison’s, “talking starts to get a bit laboured and a bit slurred” (line 61).

Prompted by the doctor to continue (“Mm”, line 62), the companion elaborated on his description and discussed some things Alison typically said at the beginning of her seizures, “And she’ll end up asking for an, an inhaler or something like that” (lines 63 to 64). He also added that he believed that the inhaler was not needed, “even if she doesn’t need it” (line 64). Hesitating, the companion then questioned, “((1 second)) do you know what I mean?” (line 65). However, before a response was offered, the companion reported Alison’s speech, “She’ll say “Oh well I need me inhaler, I need me inhaler”” (lines 65 to 66). The companion began to say more, “or” (line 66). However, before he could complete his turn, Alison interrupted (evidenced by her overlapping talk at the end of “or”) to say, “Like breathing in’t it?” (line 67). The companion’s response to Alison’s question could not be clearly heard, however, he appeared to offer a confirmation, “((mh))” (line 68).

In his description, the companion did not describe Alison’s subjective seizure symptoms per se, but gave an indication of Alison’s state, “slur her words” (line 56), “talking starts to get a bit laboured and a bit slurred” (line 61). In addition, he mentioned her “asking for an, an inhaler” (line 63), and as having said, “I need me inhaler, I need me inhaler” (line 66). These accounts appeared to influence the subjective seizure symptoms discussed in the conversation that followed.

At line 69, the doctor asked Alison to describe her subjective symptoms, “So what, what do you notice then? You, you feel not right” (lines 69 to 70). Here, the doctor’s question appeared focused on what Alison had noticed beyond ‘not feeling right’. In what may have been an attempt to move the discussion forward, the doctor then asked, “Do you feel short of breath or?” (line 70). In doing so, the doctor prompted Alison to confirm the presence of a subjective seizure symptom that not been explicitly mentioned before in the conversation. The doctor’s question appeared to arise from the companion’s mention of “inhaler” (lines 63 and 66), and Alison’s subsequent response of, “Like breathing in’t it?” (line 67). After a one-second pause, Alison confirmed that she had felt short of breath, “((1 second)) Yeah” (line 71). Following acknowledgement from the doctor, “Mm hmm” (line 72), Alison upgraded her prior confirmation, repeating, “I do, I, I do I”, and then used the terms of the doctor’s question, “feel short of breath” (line 73).

Alison went on to discuss possible reasons (“but I don’t know if it’s cos”, lines 73 to 74, “I don’t know if it’s because”, line 77 and “I think it’s cos”, lines 88 to 89) that she felt short of breath during the onset of her seizures. Alison described the subjective symptom of “panic” as possible cause, “I’m panicking like, I panic” (line 74), and added that she did, “have panic attacks anyway” (lines 74 to 75). Alison then discussed possible reasons for the “panic” she experienced. She described the onset of the seizures as sudden and unexpected, “they’re coming on that short” (lines 77 to 78) and “they come on that quick” (line 79).

Following this, Alison described her thought processes (subjective symptoms) during the onset of the last seizure she had experienced, and how these had contributed to her feeling of “panic”. These thought processes appeared to have been marked by catastrophising (as defined by Sullivan et al, 2001). Alison did not initially find giving her account easy; she hesitated (for two seconds) before she expressed, “oh how can I explain it?” (line 78). In the account that followed Alison magnified the seriousness of the event, “I had a really bad do then, a really bad do” (lines 84 to 85), and described that she felt like she was going to die, “I’m thinking oh God, is this it?” (line 79). Alison described being “quite, quite lucky” (line 81) because she had been alone at the time (“on me own”, lines 80 to 81) and had only pressed her (alert) button once to summon help (“because I only had to press my button once”, line 84). Her rumination about the experience was demonstrated when she described having considered the

possibility that had this not been the case she could have died, “um, er, if nobody had been there well I’d have swallowed me tongue and that’d have been it like” (lines 85 to 87). These descriptions conveyed a sense of helplessness. Alison described being dependent on others to ensure her safety, “if nobody had been there”. Notwithstanding the possible dire consequence of the seizure described, Alison’s negative mental set was also made evident when she described, “I know it sounds awful” (line 80). Alison linked these thoughts as having contributed to the feeling of “panic” and to the sensation of not feeling herself, “So ((1 second)) I think it’s cos I panic when I know I don’t feel right, you know” (line 88).

Following the doctor’s recognition of her description, “Mm” (line 90), Alison repeated some of the subjective seizure symptoms previously described in the conversation, and appeared to try to place these in a sequential order. Her description began with, “I start labouring more” (line 91). It was not clear as to what Alison’s use of “labouring” referred to, this might have been in relation to her feeling short of breath. On the other hand, it is notable that Alison’s companion first used the term in the conversation when he described that, “her talking starts to get a bit laboured and a bit slurred” (at line 61). In any case, Alison’s repetition of the term appeared to suggest that her account, or the terms used to describe her subjective experiences, had been influenced by her companion’s prior description. Alison went on to describe that she started “labouring more” when she panicked, “because I panic” (line 91). Alison described that panic occurred when she realised a seizure was beginning, “cos I know they’re happening” (lines 91 to 92). This realisation appeared to be primarily associated with a subjective seizure symptom she had previously described (at line 50), “I just go light-headed a little bit mainly, that’s (it)” (lines 92 to 93).

Following Alison’s description, her companion self-initiated to add, “She always seems to ask for a flannel as well” (line 94), he then went on to report Alison’s speech, ““I need a flannel, I need a flannel”” (line 94 to 95). Although Alison’s companion did not directly report a subjective seizure symptom, here again, his account influenced the question subsequently directed to Alison by the doctor. The doctor asked Alison to confirm the presence of another subjective seizure symptom that had not been previously mentioned in the conversation, “Do you feel hot?” (line 96). In response, Alison confirmed that she had experienced this

symptom (“Yes”, line 97), which was also confirmed by her companion (“Yeah, so”, line 98). However, before her companion could continue with what he had to say (Alison began to speak at the end of “so”), Alison elaborated on, and upgraded, her initial response, “Really hot” (line 99).

Following this, the doctor asked Alison to confirm the presence of another subjective symptom not previously mentioned in the conversation. He asked Alison, “Does your heart seem to race?” (line 100). Alison responded to the question with a strong confirmation, “Oh God yeah ((laughs)) I can feel that” (line 101). Following a notable pause of five seconds, in which the doctor was observed to write in the patient’s medical record, the doctor asked Alison to describe the length of time she experienced the feeling for, “And how long does this go on for, this feeling?” (lines 102 to 103). Alison responded that the feeling occurred for “about three minutes” (line 104). However, it appeared that Alison could not pin down whether she believed this to be a long time or not. Alison described the “three minutes” as both, “quite a few minutes” (line 104) and as, “it’s not much time” (line 105).

The short extract (6J) below illustrates an example of a companion who reported subjective symptoms experienced by the patient ‘in the moment’, that is, during the consultation. This was one of only two cases in the data of a companion that reported the patient’s subjective seizure symptoms in this manner. It was taken from Lawrence’s consultation, a patient with PNES, and is presented below.

Extract 6J.

14. D: Right.
15. C: And ((1 second)) right now he feels dizzy, you’ve got
16. specks in your eyes, he feels like he’s gonna collapse
17. right now.
18. D: Mm hmm.
19. C: And it just keeps getting worse.
(Doctor turned to face the patient)
20. D: ((4 seconds)) So can you take m, me back to how it
21. started?

This occurred early on in Lawrence’s consultation. In the talk before the extract shown, Lawrence described the number of times he had ‘blacked out’ and the number of times he had been admitted to hospital. The doctor acknowledged this information at line 14, “Right”. At line 15, Lawrence’s companion self-

initiated to describe that Lawrence was experiencing a number of subjective symptoms, “right now” (lines 15 and 17). The companion hesitated for a second before reporting that, “right now he feels dizzy” (line 15). She also stated that Lawrence was experiencing a problem with his vision, “you’ve got specks in your eyes” (lines 15 to 16). She then added, “he feels like he’s gonna collapse right now” (lines 16 to 17). After the doctor had offered a confirmation, “Mm hmm” (line 18), the companion described the trajectory of the symptoms Lawrence was experiencing, “And it just keeps getting worse” (line 19).

Companion descriptions of subjective seizure symptoms in the data were associated with what the companion had witnessed, what the patient had told the companion about what they had thought or how they had felt, or from inferences from one or both of these streams of information. However, without this knowledge companions struggled to provide subjective information, as is evident in extract 6K, presented below. This was taken from Karen’s consultation, a patient with PNES.

Extract 6K

252. C: Like mumbling.
253. D: Mumbling, mm hmm.
254. C: Randomly.
255. D: Mm. ((4 seconds)) And then is she back to normal or still
256. not?
257. C: Well it could take her, it could take her um ((0.5 seconds))
258. I don’t know, probably half an hour to an hour
259. to, to, to, to, to, to get back to normal.
260. D: Mm, OK.
261. C: That’s, but I’m, I’m not in her body so I don’t know.
262. D: Yeah.
((99 lines omitted))
362. D: OK. So are there any, are there any attacks where she’s
363. just like, where there’s just like the beginning of the
364. attack you described to me without the shaking and
365. trembling?
366. C: ((1 second)) Um.
367. D: You know, where you just can’t get through to her and
368. then she comes round again?
((13 lines omitted))
382. D: So that does happen but it’s difficult to know how often
383. that is because [it’s]
384. C: [I me]an I’m not in her body, I, I, I don’t know.
385. D: Mm.
386. C: I, I just see, see it from, from, from the outside um of, of,
387. of things.

In the extract above, the companion discussed Karen's vocalisations following a seizure episode, "Like mumbling" (line 252), "Randomly" (line 254). After acknowledging this information ("Mm", line 255), and writing in the patient's medical record (during which a four second pause was observed), the doctor asked the companion, "And then is she back to normal or still not?" (lines 255 to 256). In response the companion gave an 'extended answer' (Stivers and Heritage, 2001). The companion began his response with "Well" (line 257). In his extended response, the companion demonstrated difficulty explaining that Karen was not immediately 'back to normal', "it could take her, it could take her um (0.5 seconds) I don't know, probably half an hour to an hour to, to, to, to, to, to get back to normal" (lines 257 to 259). The companion's response was marked by repetition ("it could take her", "to"), hesitation and pauses ("um (0.5 seconds)"), and he also expressed that he was uncertain of how long it took Karen to return to 'normality' ("I don't know, probably").

Following confirmation by the doctor "Mm", the doctor added, "OK" (line 260); Jefferson (1981) observed that the use of OK could mark a 'moment of topic transition'. However, following this, the companion elaborated on his account, and added what appeared to be a 'caveat' to his previous description, "That's, but I'm, I'm not in her body so I don't know" (line 261). The companion clearly expressed that he could not accurately gauge Karen's return to normality ("I don't know", lines 258 and 261) following an event because he did not have access to that privileged information, "I'm not in her body" (line 261).

Later in the conversation, the companion encountered a similar problem. The doctor asked the companion if Karen experienced 'absences', "without the shaking and trembling" (lines 364 to 365), "where you just can't get through to her and then she comes round again?" (lines 367 to 368). In response (not shown in the extract), the companion confirmed that Karen experienced 'absences' and gave an example of Karen seemingly ignoring him. In his description, the companion did not report Karen's subjective experiences.

Following this, the doctor acknowledged the information given by the companion, "So that does happen" (line 382). The doctor then began to ask the companion a question about the difficulty of ascertaining the frequency of

Karen's absences, "but it's difficult to know how often that is because it's" (lines 382 to 383). However, before the doctor could complete his question, the company interrupted to respond (in overlap with the doctor at "it's"). The companion stated, "I mean I'm not in her body, I, I, I don't know" (line 384). This was a near identical repetition of the companion's earlier statement at line 261. Following acknowledgement by the doctor ("Mm", line 385), the companion went on to add, "I, I just see, see it from, from, from the outside um of, of, of things". Here again, the companion expressed that he did not have access to the privileged subjective information required to answer questions about Karen's subjective state, he could only describe what he had witnessed.

4. Discussion

The thirteen consultations analysed in this chapter involved patients with PNES (n=7) or epilepsy (n=6) who were accompanied to a neurology outpatient appointment by a spouse or partner who had witnessed at least one of their seizure episodes. The median length of the (thirteen) consultations was 24 minutes.

Analysis of the thirteen consultations found a (weak) non-significant correlation between the discourse spaces of doctors and companions. This was not surprising given that doctors in other clinical settings have been observed to deflect attempts by companions to form alliances by redirecting questions to patients or by changing topic (Coe and Prendergast, 1985). However, the finding that the discourse space of patients was not significantly associated with the verbal activities of doctors in these interactions was somewhat unexpected. Using correlation of discourse space as a proxy measure, the finding suggests that the doctor-patient alliance is weakened when a seizure-witness companion accompanies the patient in these clinical encounters.

Moreover, it was shown that patients did not speak significantly more than their companions did in these encounters. This finding does not reflect those of other studies. In other clinical settings patients have been found to occupy significantly more discourse space than companions (Wolff and Roter, 2012; Ishikawa et al, 2005a; Shields et al, 2005; Street and Gordon, 2008 and Wolff and Roter, 2011). The finding that patients did not speak significantly more than their companions did, might reflect the unique nature of the (diagnostic)

consultations studied here. It appears that, on average, companions (seizure-witnesses) in this clinical setting might make more verbal contributions than companions in other clinical settings.

Moreover, the discourse spaces of patients were significantly (strongly to very strongly) correlated with changes in the discourse spaces of companions. The relative contributions of doctors and patient-parties to the consultations were really quite stable, but there was significant variability of patient and companion contributions to the patient-party portion of the discourse spaces. It appears that companions in these interactions tended either to contribute comparatively more (31% of companions contributed more than 60%) or less (54% of companions contributed less than 40%) to patient-party talk. This may help explain why a strong to very strong inverse association was observed between the discourse space of patients and companions. Comparatively few companions occupied a 'middle ground' in terms of verbal activity in these encounters. Only 15% of companions in the data were classified as 'partners', and contributed 40% to 60% to patient-party talk.

Structurally, these results suggest that the discourse spaces of patients were wholly associated with changes in the discourse spaces of companions and not those of doctors. In addition, that the presence of a companion reduced the space available for the patient's rather than the doctor's contribution to the interaction.

Overall, these findings suggest that the presence of a companion may limit opportunities for patients to describe their seizure experiences, and hence reduce opportunities for doctors to observe the topical, linguistic and interactional features of seizure patient talk – and to use these features in their diagnostic decision making processes.

Differences in the age and gender of PNES and epilepsy patients in the study were consistent with these patient groups, and were not significant. However, PNES patient consultations were significantly longer than epilepsy patient consultations. This finding is interesting as researchers report primary care visits are significantly longer when they include psychosocial considerations, as opposed to purely biomedical discussions (Deveugele et al, 2002). Given the assumed aetiology of PNES, it may be the case that more psychosocial

discussions take place in PNES patient consultations than they do epilepsy patient consultations.

A significant difference in the ratio of PNES and epilepsy patient consultations undertaken by the two doctors participating in the interactions was, however, observed. This difference could account for the significant difference in the length of the PNES and epilepsy patient consultations, and other (potentially) differential findings in the data. The implications of this are discussed further in the limitations section of this chapter.

However, no significant differences between the discourse spaces of participants in the PNES and epilepsy consultations were observed, suggesting that the verbal activities of patients, companions and doctors in PNES patient consultations were similar to those in epilepsy patient consultations.

In addition to having similar participant discourse space structures, the consultations were found to be topically similar, regardless of whether the patient was diagnosed with epilepsy or PNES. With few exceptions, the nine topical history-taking phases identified in the data (see figure 4) were observed across PNES and epilepsy patient consultations. These history-taking phases are comparable to those described in previous research that has explored the composition of neurology (seizure patient) consultations (Kennedy and Zakaria, 2008) and those recommended by national epilepsy guidelines (NICE, 2012).

There was also broad consistency in the sequence and organisation in which history-taking phases were discussed in the consultations. However, history-taking phases often 'intersected' other consultation phases, and were not always discussed in a uniform order. There was some recurrence as well. This was particularly evident towards the end of consultations, where history-taking topics were often returned to, summarised and clarified before diagnosis, aetiology, and treatment and management recommendations were discussed. In this sense, contrary to Byrne and Long's (1984) 'ideal structure' proposal, history-taking activities were more in line with Robinson's (1998) observations, in so much as they resembled activities that needed to be accomplished before 'getting down to other business' (before diagnosis, treatment and management discussions progressed).

Four of the history-taking phases identified in the data (phases 4 to 7) became the focus of finer-graded qualitative analyses. These phases contained descriptions of attacks and discussions of periods of reduced patient consciousness and unconsciousness. As recommended in national guidelines (NICE, 2012), patients and companions were frequently observed to discuss the frequency, timing, and duration of events, seizure triggers and warnings, patient colour change, motor phenomena (movements), alterations in consciousness, and symptoms following attacks during these history-taking phases.

4.1. Companion involvement mechanisms

Authors have reported that comprehensive medical history-taking is a restrictive environment for patients' responses (Stivers and Heritage, 2001). As Heritage (2010) has noted, doctors' questions set topical and action agendas, they embody presuppositions, convey an epistemic stance and incorporate preferences. However, this is not to say that patients do not evade or resist doctors' questions. As Bolden (2009) has observed, conversational participants are "*active agents who can marshal a range of resources for resisting, problematizing, or evading agendas and presuppositions put forth by sequence-initiating actions*" (p. 122). Patients can give 'non-conforming responses' in response to questions (Raymond, 2003), they can answer 'yes' or 'no', offer no relevant information, give substantive information, explain, clarify or justify, etc. (Boyd and Heritage, 2010).

Findings from this study suggest that patients with epilepsy and PNES respond to doctors' information gathering acts differently, and there are diagnostic conversational pointers in the interaction between patients and companions (and patients and doctors) in these encounters. The companions of PNES and epilepsy patients typically used or responded to different 'interactive mechanisms' to become involved in conversations to describe what they had witnessed and tell 'their story'. These 'mechanisms' appeared to be associated with the extent to which the patient resisted answering the doctor's questions, which in turn influenced the extent to which the patient (and the doctor) were reliant on the companion to describe what they had seen.

In the majority of the epilepsy patient consultations analysed (five of six), the companion waited to be invited by the doctor to describe what they had witnessed (for example, as in extracts 6B and 6C). Conformity to this interactive structure was only observed in one PNES patient consultation (Lawrence's). In two epilepsy patient consultations, the doctor bypassed a description from the patient and instead invited the companion to describe what they had witnessed (for example, as in extract 6C). However, in these two cases it was established that the patients exclusively experienced seizures whilst they slept. In three of the epilepsy patient consultations, patients provided a description of what they had experienced before their companion was invited by the doctor to describe what they had seen (for example, as in extract 6B). Only one epilepsy patient consultation did not follow this format. In that consultation the patient (Colin) invited his companion to describe what she had witnessed before he attempted to give an account of what he had experienced.

Epilepsy patients (including those who experienced seizures whilst they slept) typically demonstrated low levels of resistance to the doctors' questions about their attacks. In epilepsy patient encounters, resistance to the doctors' questions was usually a consequence of the potentially problematic design, as opposed to the topical agenda of the questions posed.

To deal with potentially problematic question designs, epilepsy patients often 'specified the terms' (Stivers and Hayashi, 2010) of the question posed (for example, as in extracts 6B and 6C). Stivers and Hayashi (2010) have suggested that recipients that specify or narrow the terms of a question find the basic question design acceptable but as requiring qualification. Another way epilepsy patients were observed to deal with the potentially problematic design of questions posed was to provide 'extended answers' (Stivers and Heritage, 2001) and/or 'roundabout trajectories' (Clayman, 2001) (as observed in extract 6B).

Stivers and Heritage (2001) described that 'expansions' form a continuum from which the departure from (resistance to) the agenda of the question can be assessed. The authors have suggested that the most common of these 'expansions' fall into three clusters; those that address the difficulties of giving a definite answer, those that support the answer by adding details and those that

preempt negative inferences that may have arisen in the absence of elaboration.

In addition, Clayman (2001) made a basic conceptual distinction between two aspects of resistance, the negative and positive dimensions. The author suggested that 'roundabout trajectories' could represent a positive dimension of resistance. Clayman (2001) observed that 'roundabout trajectories' sometimes began with an initial response that in itself was not an answer, but when elaborated upon in a larger stretch of talk could be seen in its entirety as an answer. However, the author suggested a more common trajectory was that the recipient began with a minimal answer that filled the information gap targeted by the question, followed by subsequent talk that added additional detail and clarified, supported or elaborated on the initial response. In Clayman's (2001) schema, the positive and negative dimensions of resistance are manifest to the degree that the interviewee moves beyond the bounds of the question and elaborates on things not specifically asked for. On one end of the scale, this involves interviewees slightly changing the terms of the question to manage their response (a positive dimension), at the other end of the scale, it results in an overt and substantial change of topic (a negative dimension).

When epilepsy patients gave an extended answer (Stivers and Heritage, 2001) and/or provided a 'roundabout trajectory' (Clayman, 2001), they usually responded by elaborating and additional details that adhered to the topical agenda of the question posed. In this sense, epilepsy patients rarely responded with a 'narrative departure' (Stivers and Heritage, 2001) from the agenda of the question posed and typically stayed within (or approximate to) 'the bounds of the question' and demonstrated a 'positive dimension of resistance' (Clayman, 2001).

Epilepsy patients rarely (if ever) responded to a doctor's question about their seizure experiences by prompting their companion to answer on their behalf. And unless the patient demonstrated difficulty, for example, finding the design of the question potentially problematic (as was seen in extract 6B), doctors seldom had to prompt epilepsy patients to answer questions they had posed to them about their attacks. Epilepsy patients frequently asked their companion to confirm their accounts, though usually in relation to a specific aspect of an answer they had already given (for example, as in extract 6B).

In sum, the typical interactive behaviours displayed by patients with epilepsy in the data suggested that they were not overly reliant on their companions to describe what they had witnessed during attacks. However, in cases where patients experienced epileptic seizures whilst they slept, the patient (at least from the doctor's perspective) appeared almost wholly reliant on the companion to describe what they had seen. In these encounters, the doctor did not ask the patient what they had experienced, and instead invited the companion to describe what they had witnessed shortly after learning that the patient experienced seizures whilst they slept (as was seen in extract 6C).

These observations reflect those found in previous studies of interactions between seizure patients and doctors in which no additional person was present. In one-to-one doctor-patient interactions, patients with epilepsy have typically demonstrated that they can easily focus on descriptions of seizure symptoms and provide coherent (and detailed) accounts of individual seizure episodes. They required much less prompting than patients with PNES to describe their subjective seizure experiences (Guelich and Schoendienst, 1999; Schoendienst, 2001; Furchner, 2002 and Surmann, 2005, cited in Schwabe et al, 2008; Schwabe, Howell and Reuber, 2007; Plug and Reuber, 2009 and Plug, Sharrack and Reuber 2009a and Reuber et al, 2009).

In addition, the finding that epilepsy patients in the data frequently asked their companion to confirm their accounts, usually in relation to a specific aspect of an answer they had already given, is supported by previous research findings. Unlike patients with PNES, epilepsy patients have previously been observed to direct 'understanding checks' to doctors in one-to-one doctor-patient interactions in order to ensure that their (subjective) accounts make sense (for example, '*do you know what I mean?*' '*Does that make sense?*') (Reuber et al, 2009).

The companions of epilepsy patients were observed to self-initiate during the patient accounts of their seizure experiences. However, most of these self-initiations were minimal agreement or acknowledgement tokens that did not interrupt the patient's talk (for example, as seen in extract 6B). These were seen to demonstrate alignment with patients' accounts. Lambertz (2011), Zimmerman (1993) and Svennevig (1999) have also suggested these types of

self-initiations indicate engaged, active and/or attentive listening. Other instances of companions of epilepsy patients self-initiating their contributions tended to be in response to the patient demonstrating difficulty answering the doctor's question (as seen in extract 6B). In other clinical settings, these types of companion behaviours (responding to patient difficulty and showing agreement with patient talk) have been associated with the enhancement of patient autonomy (Clayman et al, 2005), showing support for the patient (Ishikawa et al, 2005a) and helping to facilitate doctor-patient interaction (Clayman et al, 2005).

In contrast to the majority of epilepsy patients in the sample, most of the PNES patients (five of seven) were resistant to doctors' questions about their attacks. Just like epilepsy patients, those with PNES sometimes responded to the potentially problematic design of doctors' questions about their seizure experiences by 'specifying the terms' (Stivers and Hayashi, 2010) (as was seen in extract 6Di). However, compared to epilepsy patients, PNES patients more frequently responded to the doctors questions by 'transforming the topical agenda' (Stivers and Hayashi, 2010) of questions posed. Stivers and Hayashi (2010) have viewed 'agenda-transforming' answers as demonstrating more resistance than 'term-specifying' answers.

PNES patients sometimes provided 'expanded answers' (Stivers and Heritage, 2001) in response to doctors' questions about their attacks. However, unlike those usually given by epilepsy patients, the expansions provided by PNES patients often 'transformed the topical agenda' (Stivers and Hayashi, 2010) of the question posed - for example, by focusing on one aspect of the attack, such as the situational details and circumstances of the attack or the (medical) consequences of the attack (as seen in extract 6Diii). Stivers and Hayashi (2010) consider responses that focus on one aspect of a question and not another as having shifted and 'transformed' the topical agenda of the question. In addition, Clayman (2001) suggests that recipients who avoid providing an adequate answer, whose response falls short, or does not adequately answer the question, exhibit the 'negative aspect of resistance'.

These findings reflect those of previous studies. In one-to-one doctor-patient interactions, authors observed that PNES patients tended to focus on the situational and circumstantial details of attacks (Guelich and Schoendienst,

1999; Schoendienst, 2001; Furchner, 2002 and Surmann, 2005, cited in Schwabe et al, 2008; Schwabe, Howell, and Reuber, 2007) and the dramatic circumstances or consequences of seizures (Plug and Reuber, 2009 and Plug, Sharrack and Reuber, 2009a) compared to patients with epilepsy.

It is also notable that PNES patients in the data sometimes responded to doctors questions about what had happened during attacks by stating an inability to remember or to know what had happened; for example, “don’t really remember”, “I don’t know”, “I never remember”, “I really don’t know” (as seen in extracts 6Di, 6Dii, 6Diii). These types of answers have been called ‘non-answer responses’ (Stivers and Robinson, 2006). Stivers and Robinson (2006) have observed that ‘non-answer responses’ can be responses that account for not answering a question. Likewise, many PNES patients in the data cited an inability to remember as a reason for not being able to answer a question about their seizure experiences. In contrast, patients with epilepsy were rarely observed to respond to doctors’ questions by stating an inability to remember or to know what had happened.

In previous research, authors observed that patients with PNES sometimes used ‘absolute negations’ when they describe their seizure experiences (for example, *‘I feel nothing’, ‘I do not know anything has happened’*). ‘Absolute negations’ have been described as accounts of what seizures are not like, and include denials of the ability to remember what has happened during episodes (Guelich and Schoendienst, 1999; Schoendienst, 2001; Furchner, 2002 and Surmann, 2005, cited in Schwabe et al, 2008; Schwabe, Howell and Reuber, 2007; Plug and Reuber, 2009 and Plug, Sharrack and Reuber 2009a). These types of responses are akin to what Pomerantz (1986) termed ‘extreme case formulations’. An example of a patient in the data that responded to a question about their seizure experience with an ‘absolute negation’ can be seen in extract 6Di (“I never remember what happens during a seizure”, lines 36 to 37).

Patients that responded with an inability to answer (and/or ‘absolute negations’) in the data might have done so in an attempt to ‘close down’ the conversation, which can also be considered an act of resistance to the topical agenda of the discussion. For example, Pichler (2007) has observed that “I don’t know” has a variety of functions other than a declaration of a ‘lack of certainty’ or asserting insufficient knowledge; for example, it can perform the act of ‘topic-closure’,

'topic-curtailed' and 'turn-yielding'. Similarly, responding to a question by prompting someone else to answer was considered to demonstrate strong resistance to the topical agenda of the question posed (as was seen in extract 6E), and an indication that the recipient wanted to 'relinquish the floor'. Compared to patients with epilepsy, PNES patients were more frequently observed to prompt their companion to answer a doctor's question on their behalf (for example, as in extract 6E). In the absence of an answer from the intended recipient (patient), these responses were also considered 'non-answer responses' (Stivers and Robinson, 2006) in the analysis.

There was often an assumption embedded in the doctor's question that the patient would be able to provide an answer (for example, as in extract 6Diii, "And sometimes you can remember a little bit about?" (line 52)). However, this assumption was rejected when, in response, patients stated they were unable to answer (because they did not remember or know) and/or when they prompted their companion to answer on their behalf. In Stivers and Hayashi's (2010) framework, such responses would be deemed very resistant (as the underlying assumption and topical agenda of the questions were rejected).

On a spectrum of 'negative responses', Clayman (2001) considers the strongest negative responses to be declining to comment or failing to provide any information at all in relation to a question. When patients prompted someone else to answer a question on their behalf, this was often considered a failure to provide information, and a (indirect) decline to comment. Similarly, when PNES patients responded to questions with an inability to answer, they were observed to provide little (if anything) in the way of information. An account for their inability to answer rarely extended beyond 'not remembering' (for example, see extract 6Di). Recipients that replied with these types of responses demonstrated 'strong negative resistance' and used 'overt tactics', that Clayman (2001) has described as unconcealed attempts to depart from the question's topical agenda.

The observation that PNES patients in the data more frequently responded to doctor's questions about their seizures by communicating an inability to answer, compared to patients with epilepsy, reflects findings from previous studies of one-to-one doctor-seizure patient interactions. Authors have reported that patients with PNES typically resist focusing on attacks and find it difficult to

report seizure events (Lacey, Cook and Salzberg, 2007, Reuber, 2008), especially when compared to patients with epilepsy (Guelich and Schoendienst, 1999; Schoendienst, 2001; Furchner, 2002 and Surmann, 2005, cited in Schwabe et al, 2008; Schwabe, Howell, and Reuber, 2007, Plug, Sharrack; Reuber 2009a and Reuber et al, 2009).

Patients with PNES were typically observed to resist answering doctor's questions about their attacks. This was not confined to questions about periods of reduced consciousness or unconsciousness; PNES patients frequently resisted discussing seizure trajectories (for example, as in extract 6Dii), seizure triggers and warning signs (for example as in extract 6Di), and sometimes post seizure symptoms. As described, PNES patients were often observed to respond to the doctor's questions about their attacks by claiming an inability to answer (as was seen in extract 6Di), and by 'transforming the topical agenda' (Stivers and Hayashi, 2010) of the question posed, for example, by focusing on one aspect of the question about their seizure experiences and not another (as was seen in extract 6Diii).

Given these characteristics, it is perhaps not surprising that doctors often had repeatedly to prompt patients with PNES to describe what they experienced (for example, as seen in extract 6Dii). As Stivers and Robinson (2006) have observed, recipients are 'under pressure' to provide answers and speakers will restructure their question to elicit an answer. The need to prompt patients with PNES to discuss their seizure episodes, particularly in comparison to patients with epilepsy, is reported in previous research exploring one-to-one doctor-seizure patient interactions (Guelich and Schoendienst, 1999; Schoendienst, 2001; Furchner, 2002 and Surmann, 2005, cited in Schwabe et al, 2008; Schwabe, Howell, and Reuber, 2007, Plug, Sharrack; Reuber 2009a and Reuber et al, 2009). Similarly, in chapter three of this thesis patients with PNES were found to need significantly more prompting to discuss what third parties had told them about their attacks compared to patients with epilepsy.

Discounting the use of minimal agreement and acknowledgement tokens, the companions of PNES patients in the sample typically self-initiated more talk than the companions of epilepsy patients during the 'seizure description' phases of the consultations (history-taking phases 4 to 7). In many of the PNES patient consultations, companion self-initiation appeared to be a consequence of

patient resistance to the doctor's questions (as in extracts 6Dii, 6Diii and extract 6E), and followed, for example, the patient claiming an inability to answer. As Stivers and Robinson (2006) have observed; there is *"a preference for an answer over the preference for a response from the selected next speaker ... [and] ... a common environment in which non-selected recipients provide answers to questions that selected another as next speaker is when selected next speakers claim an inability to answer"* (p383).

However, in other instances of companion self-initiation patient resistance or difficulty was not always evident. This was more frequently observed in PNES patient consultations than epilepsy patient consultations. In one case (Peter's), the patient's resistance to questions about his attacks and the reliance placed on his companion to describe what she had witnessed could not be adequately assessed due to persistent companion self-initiation (see extract 6F). However, it is notable that Peter's companion provided a (extensive) description of what she had witnessed before Peter had the opportunity to describe what he had experienced.

Companions in other clinical settings have been observed to express concerns and direct comments to doctors (Beisecker, 1989), state opinions or preferences (Street and Gordon, 2008), ask questions (Street and Gordon, 2008; Egly, 2006 and Ishikawa et al, 2005a), answer on the patient's behalf without being invited to do so (Greene et al, 2004), and comparatively more of their talk has been classified as 'active' (Street and Gordon, 2008). However, research has also suggested that companions are more verbally active when the patient's expectations of their companion's role is higher, or when companion expectations of their role is higher (Ishikawa et al, 2005a). In addition, findings from other clinical studies have suggested that a companion who considers himself or herself the patient's primary caregiver is more likely to self-initiate to become involved in interactions (Tsai, 2000).

It may be the case that patients with PNES place a greater reliance on their companion to contribute and/or that the companions of PNES patients have a higher expectation of their role in these encounters. For example, authors have observed that the lives of patients with somatoform disorders often involve a high degree of dependence (Kirmayer, Robbins, and Paris, 1994 and Kaplan and Sadock, 1998). In addition, researchers report that people with PNES

engage in avoidant coping behaviours (Frances et al, 1999), especially in comparison to people with epilepsy (Stone, Binzer and Sharpe, 2004). It is also possible that the companions (partners and spouses) of PNES patients considered themselves as the patient's 'primary caregiver'. In contrast, epilepsy patients may be less dependent on their companions, and companions may be less inclined to consider them in need of a 'caregiver'. Research has shown that people with epilepsy typically present themselves as resourceful individuals who mitigate risks and look to normalise their life with seizures (Reuber and Monzoni, 2009).

These previous research findings, and those concerning patient resistance presented here, might help to explain why the companions of PNES patients were observed to self-initiate comparatively more than the companions of epilepsy patients during the 'seizure discussion' phases of the consultations. They might also explain why comparatively more (significant) reliance appeared to be placed on the companions of PNES patients to describe what they had witnessed during attacks.

However, despite the differential potential of these conversational diagnostic pointers, findings also suggest that the presence of a companion may limit opportunities for patients to describe their seizure experiences.

When doctors in the interactions faced considerable patient resistance, often after repeatedly prompting the patient to describe an attack, they typically looked to companions to describe what they had witnessed. This occurred (much) more frequently in PNES patient consultations compared to epilepsy patient consultations. In these instances, companions were invited by the doctor to describe what they had seen (as seen in extract 6Dii), they were invited by the patient to describe what they had witnessed (and were subsequently prompted by the doctor to continue with or to elaborate on their description, as seen in extract 6E), or they self-initiated talk about what they had seen and were prompted by the doctor to continue with or to elaborate on their description (as seen in extract 6Diii). This often meant that the companions of PNES patients provided an account of what they had witnessed before the patient had described what they had experienced (if the patient ever did so).

In addition to potentially limiting opportunities for patients to describe their seizure experiences, findings also suggest that companion accounts have the capacity to obscure and influence patient descriptions of their attacks.

4.2 Subjective seizure symptoms

Despite being primarily located within the 'epistemic domain' Heritage (2012) of the patient, at least one (often several) of the patients' subjective seizure symptoms were reported by companions in all of the consultations analysed. Moreover, many of the subjective seizure symptoms reported by patients were seen to originate with (or be prompted by) companion descriptions or doctors' questions. Companions did this either directly, by reporting what the patient had told them about what they had thought or felt during, before or after an attack (for example, as in extract 6G), or indirectly, by describing the patient's subjective state from their own observations (for example, as in extract 6H) or by discussing what they had witnessed more generally (for example, as in extract 6I), which then stimulated further exchanges about the patient's subjective seizure symptoms. Prompted by companion descriptions of what they had witnessed, doctors often asked the patient about subjective seizure symptoms that had not been previously (explicitly) mentioned in the consultation (for example, as in extract 6I). These 'ways of knowing' reflect the different types of 'knowables' reported by Pomerantz (1980), those that are known from first-hand experience, and those that are known from reports and (in the case of many of the doctors questions about symptoms not previously mentioned) from inference.

When companions reported or stimulated discussion of subjective seizure symptoms not previously mentioned by patients in the consultation, or doctors asked patients to confirm the presence of, or to describe subjective seizure symptoms that had not been previously discussed, it is not known whether patients would have volunteered these without being stimulated or prompted to do so. In addition, the extent to which patients might have described their symptoms (the level of detail attached to their descriptions and the formulation effort used to describe them) had prior discussions/questions about their symptoms not occurred is unknown. In some cases patients did not go on to describe subjective symptoms after they had been introduced and discussed by their companion. However, when patients subsequently discussed subjective

seizure symptoms previously mentioned by the companion (or doctor), many of their descriptions appeared to have been influenced. For example, patients were often observed to use contexts, examples (for example, as in extract 6G), and terms (for example, as in extracts 6H and 6I) that had been previously used by their companion (or the doctor).

Repetition is a well-recognised feature of conversation. Repeating or paraphrasing a word, phrase or discourse pattern previously used by a hearer into one's own talk is often termed 'allo-repetition' or 'other-repetition' (Tannen, 1987). 'Allo-repetition' serves a number of functions in conversation. As Tannen (2007) has put it, it supports comprehension by reducing information and making the discourse less dense, it helps establish interpersonal involvement in the conversation, and it improves connection and coherence by showing how one meaning or idea is linked to another. Hearers often repeat or paraphrase a word, phrases or discourse pattern, followed by ongoing talk, in an effort to develop the conversation and move it along (Tannen, 1987). However, in the interests of identifying the differential features of seizure patient talk in routine outpatient neurology consultations where a seizure witness accompanies the patient, the tendency for repetition to occur is problematic, especially if witness descriptions are provided before patients are able to describe their experiences.

5. Limitations

The data presented in this study forms part of the larger sample described in chapter five and the data collection limitations outlined there should also be considered here.

This study is also limited in a number of other respects. Conversations were analysed in depth and in great detail, but only a small patient sample (n=13) consisting solely of seizure patients diagnosed with PNES (n=6) or epilepsy (n=7) and accompanied by their seizure-witness spouse or partner was described. In addition, two of the patients diagnosed with epilepsy exclusively experienced seizures whilst they slept. These conversations are potentially different from the others presented here. Patients that exclusively experience seizures whilst they sleep may have less to say about immediate pre-ictal symptoms. These patients and the doctors involved in these interactions may rely more on companions for a description of the events - even if these patients

could report details, their contributions may be considered less relevant than what the companion has to report, and are therefore not voiced or requested in this clinical setting.

There were no significant differences between the age and gender of participants with epilepsy and PNES in this study. However, it is important to note that patients other socio-demographic characteristics (for example, level of education, sociocultural and ethnic background) were not described and these factors may have effected their contributions to the interactions. In addition, no socio-demographic data about companions (with the exception of relationship to the patient) was collected. Moreover, little information about the nature of the relationships between partner and patient was known (for instance how long they have known each other, and how they were getting along at the time of the conversation).

In addition, the difference in the ratio of PNES and epilepsy patient consultations undertaken by the two doctors participating in this study was statistically significant. To reduce the number of follow-up patients on their caseload, one of the neurologists that participated in this study was assigned fewer new patients (initial consultations) halfway through the data collection process. These changes were made by NHS management, and were beyond the control of the neurologist and researcher. Both neurologists have worked together in the same seizure clinic for over ten years but one had a greater interest in PNES than the other, and therefore received more referrals of patients with possible PNES. These factors might help explain the significant difference in the ratio of PNES and epilepsy patient consultations undertaken by the two doctors in this study. This observation may also explain the significant difference in the length of PNES and epilepsy patient consultations.

Whilst the conversational profiles of epilepsy and PNES patients found in this study very much match those described in other studies undertaken in Germany (Guelich and Schoendienst, 1999; Schoendienst, 2001; Furchner, 2002 and Surmann, 2005, cited in Schwabe et al, 2008) and the UK (Schwabe et al, 2008; Schwabe, Howell, and Reuber, 2007, Plug, Sharrack; Reuber 2009a and Reuber et al, 2009), it is possible that some of the interactional differences between PNES and epilepsy patients observed in this study are a consequence of differences in the two doctors' consultation and communication styles.

Doctors were encouraged to use their routine interview method in the encounters. However, one of the participating neurologists had previously used the 'EpiLing' interview method, and this may have affected his communication style. This study did not specifically focus on differences in the doctors' communication styles. However, it is notable that only a 2% median difference in the discourse space of doctors that participated in the epilepsy and PNES patient consultations was observed. Had one of the doctors used a method akin to the 'EpiLing' interview method and the other had not, a greater difference would be expected. Similarly, differences in the discourse spaces of patients and companions in epilepsy and PNES patient encounters were not significant. Findings also suggested that the consultations were topically similar regardless of patient diagnosis, and the topical history-taking phases identified in the data reflected those recommended in national epilepsy guidelines (NICE, 2012).

Nevertheless, participating neurologists, patients and companions were aware that the recordings would be used to identify features that might help with the differential diagnosis of attacks. This may have affected how participants behaved in the interactions, and the encounters analysed in this study may not be representative of those in other neurology outpatient encounters.

It is also important to note that the analyst exploring these interactions (the author) was not blinded to the patients' diagnoses. The author was responsible for coordination of data collection onsite. This involved being aware of patients with seizures of uncertain aetiology that were attending the clinic for an initial (diagnostic) consultation with a neurologist that they had not met previously. The author had access to patients' medical files in order to gather this information. Letters of referral to the clinic included reasons for referral and often cited a proposed (albeit uncertain) diagnosis and the results of previous tests. The author was also responsible for obtaining written consent from participants, indexing participation in the study in the patients' medical records, having the recordings transcribed, and anonymising the resulting transcripts. In the majority of the consultations recorded (and all those discussed here), a firm or tentative diagnosis was delivered. In addition, the author was responsible for contacting participating neurologists six months after the patient had attended their consultation to obtain the 'final' diagnosis. In practice, it was not possible

for the author to remain blinded to diagnoses. The implication of this is that the author might have been unintentionally biased when interpreting the data.

Furthermore, a lack of comparative data means that findings have been substantiated by studies that took place in different settings, with different patient groups, in which different research methods have been used. For example, previous UK research that has examined diagnostic differences in seizure patient has taken place in (inpatient) video-EEG suites, has focused exclusively on one-to-one doctor-patient interactions, and the 'EpiLing' interview method was used to collect data (Schwabe et al, 2008; Schwabe, Howell, and Reuber, 2007; Plug and Reuber, 2009; Plug, Sharrack and Reuber, 2009a, 2009b, 2012; Monzoni and Reuber, 2009 and Reuber et al, 2009).

Another possible drawback of the current study (as with the 'German data': Schwabe et al, 2008; Guelich and Schoendienst, 1999; Schoendienst, 2001; Furchner, 2002 and Surmann, 2005) is that medical diagnoses were not exclusively based on "gold-standard" evidence (the video-EEG recording of a typical seizure). The diagnoses were based on a Consultant Neurologist's clinical opinion based on all available evidence (including inter-ictal EEG and brain imaging in all cases, and video-EEG recordings in a limited number of cases).

For all these reasons the results of this study are likely to be limited.

6. Conclusion

Despite these limitations, this exploratory study extends what is known about interactions between seizure patients, seizure-witness companions and doctors in initial (diagnostic) neurology outpatient (seizure clinic) encounters.

The research findings hint at some 'diagnostic losses' in accompanied interactions in this clinical setting, for instance when companions intervene in patient accounts or when they introduce symptoms or topics not previously mentioned by patients. In addition, patient discourse space is more limited in the presence of a (seizure-witness) companion. Consequently, compared to one-to-one doctor-patient interactions, there may be fewer opportunities for clinicians to identify the differential interactive, linguistic and topical markers of

seizure patient talk that help distinguish between these seizure disorders in triadic encounters.

However, the findings also demonstrate that, unlike patients with epilepsy, patients with PNES show resistance to the doctor's questions in the form of focusing resistance and 'detailing block'. This is important, as it suggests that the findings previously made in somewhat unnatural research interviews (clinical encounters in video-EEG suites in which the 'EpiLing' interview method was used) can be diagnostically helpful in 'naturally occurring' seizure clinic interactions. In addition, the observations made here suggest new potential diagnostic pointers relating to the interaction between participants in these encounters.

Excluding patients that experience seizures whilst they sleep, doctors in interactions with seizure patients that are accompanied by a seizure-witness may notice that they are more reliant on the companions of PNES patients, than those of epilepsy patients, to describe what they have witnessed. Compared to patients with epilepsy, patients with PNES may appear more resistant to answering questions about their attacks. PNES patients may be more inclined to respond to questions about their attacks by describing that they are unable to remember what has happened, or to transform the topical agenda of the question posed. In contrast, patients with epilepsy may be more open to describing their experiences, and to ask their companion to confirm the accounts they give. Patients with PNES may appear more inclined to invite or prompt their companion to answer questions about their attacks on their behalf. Consequently, doctors may find themselves more frequently (often repeatedly) needing to prompt patients with PNES to describe their experiences, whereas this may be less likely in epilepsy patient consultations.

Doctors may also notice that the companions of PNES patients have a greater tendency to intervene in the conversation compared to the companions of epilepsy patients. The companions of patients with PNES may be more inclined to self-initiate to describe what they have witnessed, to interrupt the patient, or answer questions intended for the patient without being asked to do so. In contrast, the companions of epilepsy patients may be less likely to intervene in patient accounts, and to wait for the doctor to invite them to describe what they have seen. They may, however, offer more minimal agreement or

acknowledgement tokens than the companions of PNES patients when patients describe their attacks.

These findings provide candidate differential diagnostic pointers that could be explored in future, larger, 'rater-blinded' studies.

In addition, the finding that both patients with epilepsy and patients with PNES (and their seizure witness companions) often appeared to find the design of the doctors' questions potentially problematic suggests that doctors might want to consider taking different approaches to history-taking in these types of clinical encounters. Similarly, the finding that patient descriptions of their seizure experiences can be limited, obscured and influenced by witness descriptions (and questions from doctors) indicates that doctors might want to think carefully about the order in which they elicit descriptions from patients and companions, and the questions they pose to them.

Questions also remain as to whether it would be possible for doctors to use the 'EpiLing' interview method (or other semi-standardised approaches to history-taking) in consultations where a companion accompanies the patient - for example, how could doctors manage companion involvement in these encounters in order to better utilise the differential features of seizure patient talk in their decision making processes?

In the concluding chapter of this thesis (chapter seven), findings from this research project are considered in the context of study limitations, avenues of future research, and the implications for clinical practice. Recommendations as to the potential structure and format of accompanied interactions, should doctors want to incorporate the differential interactive, linguistic and topical markers of seizure patient talk in their diagnostic decision making processes, are also presented.

Chapter seven: Conclusion

1. Introduction

Despite impressive increases in biomedical technologies, history-taking remains a key tool in the diagnosis of patients presenting with transient loss of consciousness (TLOC), and the differentiation of epileptic and psychogenic non-epileptic seizures (PNES) in particular. However, most of the research that has explored the differential diagnostic potential of history-taking with these groups of patients has tended to focus on the factual content of patients' seizure descriptions. This research has shown that many clinical items traditionally used by doctors to inform their diagnosis (such as whether seizures occur from sleep or involve pelvic thrusting) have little or no predictive value in the differentiation of epilepsy and PNES (Geyer, Payne and Drury, 2000 and Duncan et al, 2004). This may be one reason why the majority of patients with PNES continue to receive an initial, inaccurate diagnosis of epilepsy, and why approximately 25% of patients carrying a diagnosis of epilepsy probably do so erroneously (NICE, 2012).

In view of this, researchers and clinicians have recently turned their attention to the differential potential of *how* people with seizures describe their attacks.

2. The differential potential of interactional features in seizure patient talk.

Findings from the scoping review reported in chapter two indicated that within the (wider) field of diagnostic differentiation of seizure conditions, the exploration of the differential linguistic and interactive characteristics of seizure patient descriptions is a marginal and still nascent area of research. Nevertheless, a notable body of literature was eventually identified.

Doctor-patient interactions have been studied by microanalysts since about the 1960s and research findings have inspired important changes in clinical communication (Heritage and Maynard, 2006). However, much of the research undertaken by the 'EpiLing' and 'Listening to people with seizures' project teams (and the empirical research presented in this thesis) has gone further than previous microanalytic studies - and is novel in having explored the

conversational and interactional features of patient talk as a diagnostic decision making tool.

In chapter two it was concluded that there was convincing evidence to show that PNES and epilepsy patients display distinct communication profiles and there are diagnostically relevant linguistic, interactive and topical differences in how people with PNES and epilepsy describe their attacks. The findings from these studies make a useful contribution to the multi-dimensional process of diagnostic decision-making in seizure clinic settings.

Perhaps the most substantial and convincing research supporting this case was the blinded, prospective multi-rater study undertaken by Reuber et al (2009). Using a diagnostic scoring aid (DSA) based on the findings of previous qualitative studies, two linguists predicted 85% (17 out of 20) of diagnoses correctly and the differences in mean DSA scores were significant for both raters. This was particularly impressive given that only 40% of the participants carried a correct diagnosis before admission for video-EEG.

However, of the four DSA items that explored formulation effort in the multi-rater study (Reuber et al, 2009), only one item proved significant for correct classification (for one rater). This does not correspond with the findings of several qualitative studies that have identified formulation effort as a diagnostically differential feature of patients' descriptions of their attacks (Gülich and Schoendienst, 1999; Schoendienst, 2001; Furchner, 2002 and Surmann, 2005, cited in Schwabe et al, 2008; Watson et al, 2002; Schwabe, Howell and Reuber, 2007; Plug and Reuber, 2009 and Plug, Sharrack and Reuber, 2009a). It was therefore suggested that further qualitative work, the development of different or more defined operational definitions, and quantitative testing of these, was required before formulation effort could be proposed as a reliable distinguishing feature of seizure patient talk in a quantitative model such as a DSA.

Nevertheless, in the time since the review was completed, the potential of using language analysis in the differential diagnosis of patients with epilepsy and patients with PNES has been further supported by a study of Italian patients presenting with seizures. Replicating Reuber et al's (2009) methods, Cornaggia and colleagues (2012) predicted the correct seizure diagnoses of nine out of ten

seizure patients on the basis of close, transcript-based linguistic analysis. The authors reported 90% concordance between the linguistic diagnostic hypothesis and the clinical video-EEG diagnosis. Unfortunately, the results of individual DSA items were not presented in the paper; hence, the contribution of the formulation effort items to the final diagnostic hypothesis formulated by the analysing linguist could not be assessed. Nevertheless, the findings of Cornaggia and colleagues (2012) do add credence to the use of a DSA in this clinical setting, the differential diagnostic potential of linguistic, interactive and topical differences in seizure patient talk as a diagnostic decision making tool, and support the application of these differential findings to populations whose language is not of Anglo-Germanic origin.

The literature review revealed that, whilst previous work had alerted researchers (and neurologists) to the important role that references to people who are not present during the conversation (third parties) can play, these references had not previously been examined or described in detail. Only a small proportion of the studies identified for inclusion in the review examined third party references in any meaningful way, and most discussed third party references as a point of interest within the scope of other research objectives.

The differential features of seizure patient talk were classified as falling into two broad thematic categories: 'interactive resistance' and 'subjective capacity'. These two features, particularly that of 'subjective capacity', were considered a useful focus for exploring differences between how people with epilepsy and PNES reference third parties when they describe their seizure experiences.

Two relatively unexplored features of seizure patient talk, aligned with the concept of 'subjective capacity,' emerged from the review as showing promising differential potential: 'emotional displays' and 'coping skills'. It was considered that the differential potential of these features should be investigated in future studies that examine differences between how people with epilepsy and PNES describe their seizure experiences. Moreover, whether these concepts could provide a platform from which to explore the differential potential of third party references was identified as a fruitful line of enquiry.

Based on findings from the literature review and the themes developed from these, a hypothesis was formed that people with PNES might use third party references in more negative contexts than people with epilepsy, who might reference third parties in more positive contexts. In addition, it seemed important that an analysis of third party reference use should not be confined to patients' descriptions of their attacks (for example, periods of reduced consciousness or self-control). Rather, analysis should include other descriptions associated with their perceptions and experiences of their seizure condition, especially those in which third party references were likely to feature, such as the situations and circumstances in which seizures had taken place, the consequences of attacks, descriptions of previous medical treatment, coping styles, and the social and emotional impact of the condition on patients day-to-day lives.

3. Distinguishing features of third party references in doctor-seizure patient encounters.

The empirical study presented in chapter three explored the distribution and use of third party references in 20 one-to-one doctor-seizure patient encounters using qualitative content analysis methods. This chapter describes the first study to investigate the differential potential of third party references in encounters with participants experiencing refractory seizure disorders.

Over 95% of the (536) third party references identified in the data were made in relation to patients' seizure experiences or their seizure condition. No significant differences were observed between the frequency of these references or those made spontaneously by patients with epilepsy or patients with PNES. However, patients with PNES were significantly more likely to be prompted to discuss third parties in relation to seizure episodes or their seizure condition compared to people with epilepsy. This finding is consistent with the literature, previous research has suggested that unlike patients with epilepsy, patients with PNES typically display 'focussing resistance' and 'detailing block' and need much more prompting than those with epilepsy to discuss their seizure experiences when they talk to a doctor about their attacks (Schwabe et al, 2008; Schwabe, Howell and Reuber, 2007; Plug, Sharrack and Reuber, 2009a and Reuber et al, 2009).

No significant differences were observed between the frequency of third party references used by diagnostic groups to reference their 'partner', 'family' members, 'friends and acquaintances' (or 'socially intimate' references), 'unknown others' or persons in 'medical', 'employment', or 'other institutional' contexts in the data. For the reasons discussed in chapter three, it was not possible to differentiate between the orientation and use of these references in such a way that coding could adequately be performed. However, research has shown that, compared to epilepsy patients and healthy controls, family dysfunction, trauma and abuse is higher in PNES patient populations (Alper et al, 1993; Griffith, Polles and Griffith, 1998; Krawetz et al, 2001 and Fiszman et al, 2004; Thompson's et al, 2009; Reuber, 2008 and Lesser, 2003). This suggests that differences between how and why these patients reference particular categories of third parties when they talk to doctors about their seizures would be a topic of interest for future studies.

Initially derived from the hypothesis that people with PNES might reference third parties in more negative contexts than people with epilepsy, who might reference third parties in more positive contexts (a hypothesis that emerged from the literature review presented in chapter two), two concepts seemed to suggest a significant difference between the two diagnostic groups: 'normalisation' and 'catastrophisation'. It was found that patients who used third party references in accounts in which they 'catastrophised' their experiences and their life with seizures were significantly more likely to have PNES, whilst patients who used third party references in accounts in which they normalised their experiences and their condition were significantly more likely to have epilepsy.

'Normalisation' tendencies have previously been described in a study of how patients with epilepsy cope interactionally with their condition as they talk to their doctor about it (Reuber and Monzoni, 2009). In addition, previous research has shown that, unlike people with epilepsy, people with PNES tend to focus on the negative aspects of their seizure disorder, such as the dangerous or embarrassing situations in which their seizures have occurred, the consequences of having seizures, (Plug and Reuber, 2009 and Plug, Sharrack and Reuber, 2009a) and their dissatisfaction with previous treatment (Plug, Sharrack and Reuber, 2009c). However, no studies of catastrophisation in

doctor-patient interviews about seizures had previously been undertaken. Moreover, the differential diagnostic potential of normalisation and catastrophisation has not been previously explored in this medical setting.

These findings inform existing models of interactional criteria that help distinguish between these seizure conditions. The findings have been included in International League Against Epilepsy (ILAE) guidelines that recommend minimum requirements for the diagnosis of PNES (LaFrance et al, 2013).

In addition, the findings may help researchers and clinicians better understand how people with PNES and epilepsy experience seizures and cope with their condition. This appears to be particularly true of patients with PNES. The emotional and psychological insights associated with displays of catastrophisation may help clinicians to offer more targeted support, and contribute to the treatment and management of PNES. Findings from the study have been included in research papers that have explored how people with PNES and epilepsy experience and cope with a seizure disorder (Korczyński et al, 2013) and those that discuss the aetiology, diagnosis, treatment and management of PNES (Oto et al, 2013 and Reuber et al, 2014).

4. Accompanying persons in medical interactions.

Doctor-patient interaction is a well-established field of study (Heritage and Maynard, 2006), however, exploration of accompanied medical interactions is a marginal area of research. In addition, despite the important roles companions and seizure witnesses often play in diagnostic encounters between doctors and seizure patients (NICE, 2012; Leach et al, 2005; Smith, Defalla and Chadwick, 1999 and Chowdhury, Nashef and Elwes, 2008), no known studies have previously examined accompanied encounters in a seizure clinic setting.

Consequently, the literature review presented in chapter four of this thesis aimed to assess the effects of companions in interactions between patients and doctors in other clinical settings. The methods used by researchers to analyse observational data of accompanied encounters was a particular focus of the review. These findings helped to guide the analytical approach to the seizure clinic data studied later on in the project. Part of this analysis included exploring the extent of the contributions of patients and accompanying persons to

interactions in different clinical settings, and the influence of clinical and demographic characteristics of patients and companions on the extent and nature of patient and companion contributions. These findings were used to help assess the extent to which studies of accompanied interactions in different clinical areas are comparable – and could be compared to seizure clinic data.

In keeping with the overall aims of the research project, a staged approach was taken to analysis. The specific methods used by analysts to explore accompanied interactions (with child patients or adult patients) were only assessed if the study analysed observational data as part of its research framework. In the final stage of the analysis, the effect of companion involvement was only examined if observational studies used audio or video recorded data of interactions with accompanied adult patients. The contributions of companions in these interactions were analysed thematically, and resulted in five topical areas of discussion: 1) duration and participant discourse spaces, 2) formation of coalitions, 3) role of the companion, 4) topical areas of discussion, and 5) participant behaviours and patient outcomes. Following this, possible reasons for the variability of the findings, and the extent to which studies are comparable was considered.

Studies of accompanied interactions in medical settings far removed from a neurology outpatient environment (such as psychiatry, psychology, couple or family therapy, emergency room, and palliative care settings) were excluded from the review. Nevertheless, despite the limitations imposed as part of the review design, the review was more inclusive than those that had previously examined accompanied interactions with adult patient populations. Previous accompanied patient reviews and theoretical frameworks tended to focus on paediatric (Tates and Meeuwesen, 2001; Cahill and Papageorgiou, 2007a and Gabe et al, 2004) or older adult patient (over 60-65 years of age) populations (Adelman, Greene and Charon, 1987; Beisecker, 1996 and Fortinsky, 2001). Excluding interactions in oncology settings, the review demonstrated that these patient groups (children and older adult patients) were the most likely to be accompanied to medical visits.

With regard to accompanied adult patient interactions (of 'all ages': over 18 years of age), Street and Millay (2001) presented a theoretical framework to support the analysis of these encounters. However, the only review identified

that included studies of accompanied adult patients of 'all ages' was a meta-analysis (Wolff and Roter, 2011). To qualify for inclusion in the meta-analysis, studies had to present quantitative results regarding the duration and/or structure of visits, participant communication behaviours and/or patient care outcomes. The review presented in chapter four of this thesis was not limited in these respects and initially examined studies that used a wide variety of research methodologies to investigate a variety of accompanied patient groups (including adult and child patient groups). In addition, a variety of different studies of accompanied adult patient interactions that used a number of different (quantitative, qualitative and mixed) methodologies were examined.

Since the review was completed, a systematic review of doctor–patient–companion communication has been published (Laidsaar-Powell, 2013). The systematic review included quantitative and qualitative studies that explored physician–adult and patient–adult companion (triadic) communication. Triadic encounters with healthcare professionals other than physicians (for example, psychologists or nurses) were excluded. The review was also restricted to studies that described cognitively competent adult patients; studies of patients with Alzheimer's disease or dementia were excluded.

The authors identified 52 studies for inclusion. 15 of these were observational studies of audio-or video recorded interactions between doctors, (adult) patients and accompanying persons. The remaining studies identified by Laidsaar-Powell and colleagues (2013) used focus group, interview or survey based methods, and a fair proportion of these examined interactions in palliative care and end of life settings (studies that took place in palliative care and end of life settings were excluded from the review presented in chapter four of this thesis).

Excluding studies of patients with Alzheimer's disease, dementia and those that had taken place in memory clinic settings, 17 observational studies that analysed audio or video recorded encounters of accompanied adult patients were identified for inclusion in the review presented in this thesis.

With regard to accompanied adult patient interactions, a number of parallels can be drawn between the findings presented by Laidsaar-Powell et al (2013) and those found in the review here. Both reviews described and discussed studies in terms of the methods used (quantitative, qualitative, and mixed methods).

However, given the different aims of the reviews, the review presented here discussed the different methodologies used by analysts (including those used in paediatric settings) and the comparability of studies in considerably more depth than Laidsaar-Powell and colleagues (2013) did. Likewise, Laidsaar-Powell et al (2013) included discussion of decision-making processes, which was not a focus of this project.

In addition, the reviews presented here and conducted by Laidsaar-Powell et al (2013) both concluded that the majority of observational studies of adult patient interactions have taken place in oncology settings, and that observational studies of accompanied adult patient interactions have tended to focus on older patient groups (over 65 years). Both reviews also found that the majority of studies undertaken in this area have used quantitative methods. In addition, both found that process analysis (and to a lesser extent, content analysis) has proved the most popular method for analysing observational data of accompanied adult patient interactions.

The review presented in this thesis determined that methodological flexibility was required in the study of accompanied interactions, and that methods should not be applied simply because of perspective or comfort. It was identified that there was a deficit of observational studies that used qualitative methods to analyse accompanied clinical interaction data, and that qualitative (especially microanalytic) research could add much needed insights not accessible to quantitative researchers. However, studies that used mixed method frameworks to analyse observational data were particularly welcomed. Authors have called for methods that include multiple approaches in order to study the multiple levels at which exchanges of meaning occur since at least the 1980s, including analysis of the context, sequence of interaction, form and content of interactions (Coe and Prendergast, 1985). Moreover, authors have called for methods that bridge the schism between process and content analysis, and microanalytic methods (Roter and Larson, 2002).

The review presented in this thesis found that disparities between the results of the observational studies examined may be due to differences in study methodologies, study settings (e.g. primary, secondary or specialist care, rural or urban settings, and country of origin), the nature of consultations (e.g. initial, routine or follow-up visits), patient and companion characteristics (e.g. age,

diagnoses, care needs), patient-companion relationships, and the year(s) in which studies were conducted (as relating to changes in social, cultural and institutional frameworks). These differences may mean that findings cannot be directly compared to one another, should be likened with caution, and that the generalizability of findings from individual studies is likely to be limited.

Nevertheless, there are consistencies in study findings across different reviews of accompanied adult patient literature. The review presented in this thesis and those conducted by other authors (Wolf and Roter, 2011 and Laidsaar-Powell et al, 2013) found that adult patients are usually accompanied to visits by their spouse or partner. In addition all reviewers found, that older patients, those with poorer health status, and those with lower incomes and educational attainment are more likely to be accompanied to visits. However, these differences were not applicable or were less apparent in oncology settings.

All three reviews also concluded that the role of companions and the attitudes of patients, companions, and physicians towards companion involvement, were largely dependent on patient, companion, and consultation characteristics. Despite the potential negative consequences of companion involvement (such as reduced patient discourse space and domineering or dominant companion behaviours), all three reviews concluded that the impact of companion involvement on patient and physician ratings was predominantly positive. The similarity of these findings is encouraging as they help validate the results and conclusions (regarding the effects of companionship) of the literature review presented in chapter four of this thesis.

Wolf and Roter (2011) and Laidsaar-Powell et al (2013) also recognised that there has been little synthesis of information in the area of accompanied adult patient interactions. The literature review presented here helps to address this shortfall. However, it is apparent that these reviews (and the review presented here) did not include studies of interactions between adult patients, their companions and psychiatrists or psychologists. Studies of these interactions might provide additional insights as to the effects of the presence of companions in clinical encounters, and authors might want to consider incorporating these types of studies in future reviews of clinical interactions with accompanied patients.

5. Accompanying others in seizure clinic encounters.

The research presented in chapters five and six of this thesis helps to address the deficit of observational studies that have explored accompanied adult patient interactions, especially outside oncology settings. In addition, the study samples explored in these analyses consisted of adults of 'all ages' (over 18 years of age), and this patient population is under represented in studies in this area.

48 patients (and where applicable, their companions) referred to a specialist outpatient seizure clinic because of a seizure disorder of uncertain aetiology for an initial consultation with one of three consultant neurologists whom they had not met previously consented to participate. The interactions were video-recorded and verbatim transcripts of all recordings were produced.

This type of data had not been examined previously. Earlier studies of the diagnostically differential features of seizure patient talk have tended to take place in specialist (video-EEG) settings, and doctors participating in previous studies used the 'EpiLing' interview method to gather data (take the history). The encounters studied in this project were gathered from an outpatient neurology clinic and participating doctors were instructed to use their usual (routine) communication method. Moreover, unlike the interactions explored here, earlier studies had exclusively examined one-to-one doctor-patient interactions. No known studies had previously explored the effects of companions in seizure clinic encounters.

5.1 Duration and structure of initial (diagnostic) accompanied and unaccompanied neurology outpatient encounters.

To begin to understand the effects of companions in this setting, a quantitative analysis was undertaken to determine how patient discourse space was affected in accompanied interactions. In initial (diagnostic) encounters where companions are present and a routine history-taking method is used, patient discourse space – the space available for patients to describe their experiences, may be reduced. This may have meant that the obvious benefits of having access to a companion's account could be reduced by the loss of

diagnostically important information associated with patients' descriptions of their attacks in these encounters.

The study presented in chapter five of this thesis is the only known research from the UK to explore differences in the duration of unaccompanied and accompanied medical consultations, one of only a handful internationally to investigate differences in participants' discourse spaces, and the only known study to explore these features in a neurology out-patient (and seizure clinic) setting. The study also advanced what is known about 'structural differences' in these types of interactions by exploring associations between participant discourse spaces and the strength, direction and significance of discourse space correlations. No known studies had previously explored accompanied and unaccompanied interactions using these methods.

Of the 48 interactions analysed, 18 patients attended alone and 30 patients were accompanied. No significant difference was observed between the duration of unaccompanied and accompanied interactions in the data. However, the presence of a companion was found to significantly reduce (over half) the discourse space available to patients in accompanied interactions. Patients occupied significantly more discourse space than companions in the accompanied interactions did. The results suggested that 20% of companions in the sample were considerably more verbally active than the patients they accompanied, contributing more than 60% to patient party talk. Doctors occupied significantly more discourse space than patients or companions in the accompanied interactions. In addition, the median discourse space occupied by doctors was nearly 10% greater in accompanied interactions; however, this was just beyond the bounds of statistical significance ($p < 0.06$). No significant correlation was observed between the discourse space of doctors and companions in the data. However, the discourse spaces of patients and companions, and to a lesser extent, those of patients and doctors, were significantly (inversely) correlated.

In sum, the results showed that in the seizure clinic, doctors might have to do more 'verbal work' in encounters where patients are accompanied. Moreover, that the discourse space of accompanied patients is significantly reduced in these encounters, and primarily determined by the contributions of companions, and to a lesser extent, doctors.

5.2 The effects of spouse or partner seizure-witness companions in seizure-clinic encounters.

In encounters with seizure-witnesses, the discourse space of patients is likely to be constrained further. In the 13 consultations analysed in chapter six, no significant difference was observed between the discourse space of patients and their spouse or partner (seizure-witness) companions. Thus patients did not speak significantly more than their companions did - and nearly one-third of companions in the encounters contributed more verbally (over 60% of the patient-party talk) than the patients they accompanied.

In the larger sample analysed in chapter five, correlation of patient and doctor discourse space was observed to be significant in the accompanied encounters. This significant correlation appeared to substantiate, from the doctor's perspective, the patient-doctor relationship as the primary alliance in these interactions. However, no significant correlation was observed between the discourse spaces of doctors and patients accompanied by their spouse or partner (seizure-witness) companion. Moreover, a strong to very strong (inverse) correlation was observed between the discourse space of patients and their seizure-witness companions. These findings suggested that the verbal activities of patients accompanied by a (spouse or partner) seizure-witness are entirely associated with the verbal activities of companions, and not those of doctors.

Reductions in patient discourse space and the influence of companion verbal activities on those of patients (especially those accompanied by seizure-witnesses) may reduce opportunities for doctors to observe the differential interactional, linguistic and topical features of seizure patient talk described in studies of one-to-one doctor-seizure patient interactions.

Moreover, it was established in chapter six that companion accounts have the capacity to obscure, limit and influence those of patients. This conclusion was based on the analysis of a recognised differential feature of seizure patient talk, subjective seizure symptoms. In the data, companions often reported what the patient had told them about what they had thought or felt during, before or after an attack, they described the patient's subjective state from their own observations, or they discussed what they had witnessed more generally, which

then stimulated further exchanges about the patient's subjective seizure symptoms. In some cases, the patient did not subsequently describe their experience of the symptom(s) after the companion had introduced them. In other cases, doctors asked patients about (subjective seizure) symptoms that had not been previously (explicitly) mentioned in the conversation. When the patient subsequently discussed subjective seizure symptoms that had been introduced by the companion and/or prompted by the doctor, they often used contexts, examples and terms previously used by the companion or doctor rather than trying to find their own ways of communicating their experiences.

Other previously identified diagnostically differential features of seizure patient talk were not examined in the same way. However, it is anticipated that many (if not all) of the previously recognised features of seizure patient talk (those described in chapter two) have the capacity to be influenced, obscured or limited when patients are accompanied to their visit by a seizure-witness.

For example, the effects of companion involvement may make it difficult for the doctor to identify whether the patient had volunteered a description or had been stimulated or prompted to discuss something. If the patient was prompted or stimulated to discuss a feature, there is no way to know if it would have been discussed in the absence of the companion's (or doctor's) talk. If the patient subsequently discussed something previously described by the companion, would the companion's description be taken into account, and the influence of this considered? How would the patient's formulation effort and the level of detail attached to their description be assessed under such circumstances, especially if the companion intervened in the patient's account? As described in chapter two, these topical, linguistic and interactional markers are central to how the differential features of seizure patient talk are interpreted in one-to-one doctor-seizure patient interactions. All this means that the important diagnostic contributions companions can make in first encounters between neurologists and patients with seizures might come with a cost.

However, these (possible) drawbacks may be somewhat tempered by the potential diagnostic pointers identified between the interactions of patients and companions (and patients and doctors) in these interactions. Key diagnostic communication differences described in previous studies in which a doctor and patient were present were still evident in the routine outpatient consultations in

which a seizure-witness was present, for example, in relation to 'focusing resistance', 'detailing block', and the need for patients to be prompted to discuss their experiences. In addition, potential diagnostic pointers relating to the interaction between participants in these encounters were identified.

In encounters where patients are accompanied by a seizure-witness, doctors may notice that, compared to patients with epilepsy, patients with PNES are more likely to display focusing resistance and a 'detailing block'. PNES patients may appear resistant to answering questions about their attacks. They might be inclined to describe that they are unable to remember what has happened, or to transform the topical agenda of the question posed. They may also invite or prompt their companion to answer questions about attacks on their behalf. Epilepsy patients may be less likely to respond in these ways and more open to describing their experiences themselves – although they may be more inclined to ask companions to confirm the accounts they give. Consequently, doctors may find themselves more frequently (often repeatedly) needing to prompt patients with PNES to describe their experiences, whereas this may be less likely in interactions with accompanied epilepsy patients. Hence, doctors may notice that they are more reliant on the companions of PNES patients, than those of epilepsy patients, to describe what they have witnessed.

Doctors may also notice that the companions of PNES patients have a greater tendency to intervene in the conversation compared to the companions of epilepsy patients. The companions of patients with PNES may be more inclined to self-initiate to describe what they have witnessed, to interrupt the patient, or answer questions intended for the patient without being asked to do so. In contrast, the companions of epilepsy patients may tend to wait for the doctor to invite them to describe what they have seen; they may, however, offer more minimal agreement or acknowledgement tokens than the companions of PNES patients when patients describe their attacks.

A number of limitations were established in the study described in chapter six. Perhaps the foremost of these was the significant difference in the ratio of PNES and epilepsy patient consultations undertaken by the two doctors participating in the study. Moreover, the analyst (author) was not blinded to patients' diagnoses, and only basic clinical and socio-demographic data about patients and companions were collected. In addition, only seizure patients who

were accompanied by a spouse or partner who had witnessed a seizure episode were examined in the study – this meant that only 13 encounters were analysed for this chapter of the thesis. As Laidsaar-Powell et al (2013) have pointed out, no known studies have examined differences between different types of third parties (e.g. spouse versus adult child). It may be that seizure-witnesses that are not the spouses or partners of patients display different interactive behaviours in seizure clinic encounters.

Despite similarities in topical content and the discourse spaces of participants in the epilepsy and PNES encounters examined in the analysis, this means that, before the new differential diagnostic features described in the study can be recommended for use, they should be confirmed in larger prospective studies in which analysts would be blinded to the medical diagnoses. It would be important to ensure that, in future studies, interactions with several doctors are studied and that encounters with each doctor involve patients with epilepsy and PNES. Ideally a future study would be sufficiently large to include different types of seizure-witnesses and non-witness companions. The approach of initial non-blinded analyses followed by a confirmatory study with multiple blinded raters could replicate the approach taken with the one-to-one interview data from the seizure clinic.

6. Accompanying others in seizure clinic encounters – future directions and recommendations.

Additional information that may help future studies in this area can be drawn from the analyses presented in chapters five and six. For example, the microanalytic findings point to the importance of how doctors take the history from patients (and companions), and suggest that doctors need to be mindful of their history-taking styles.

Heritage (2010) has observed that the doctors' questions in the history-taking phases follow a branching structure; in a process of hypothesis testing, potential diagnoses are pursued and ruled out. Doctors tend to use closed questions in order to do this: doctors use of closed questions has been found to be two to three times more common than that of open-ended questions in clinical interactions (Roter and Hall, 1992). However, closed questions are often associated with a certain asymmetry typically observed in doctor-patient

interactions (Chimombo and Roseberry, 1998). Moreover, the use of closed questions has been shown to limit patients' 'action agendas' (Boyd and Heritage, 2006) and the expression of patients' concerns (Heritage, 2011).

The type of questions posed by doctors is particularly important in initial (diagnostic) interactions with seizure patients. The use of closed questions is likely to effect how patients subsequently describe their experiences, and inhibit assessment of whether patients volunteer talk about their seizures and seizure symptoms. For example, it was shown in chapter six that doctors often asked patients about (subjective seizure) symptoms that had not been previously mentioned in the conversation. In response to these questions, patients were frequently observed to describe symptoms using the terms previously used by doctors.

In contrast, open-ended questions are designed to introduce an area of enquiry but allow patients to respond and shape the content of their response in their own way. In addition, the use of open questions during the initial problem presentation phase of consultations has been positively associated with increased patient satisfaction – and higher patient ratings of doctors listening skills and affective-relational communication (Robinson and Heritage, 2006).

The use of open-ended questions (albeit in a more structured way) is also encouraged in the 'EpiLing' interview method developed to facilitate the differential diagnostic use of linguistic analysis in the seizure clinic. As described in chapter two, this method deliberately discourages the use of closed questions, especially during the initial phases of encounters, in favour of open-ended questions that allow patients to set their own agendas and to choose which features of their experiences they emphasize and focus on (Schwabe, Howell and Reuber, 2007).

Moreover, in chapter six it was shown that patients with epilepsy and patients with PNES (and their companions) often found the design of the doctors' questions potentially problematic. This occurred when, for example, doctors asked a closed-question that the patient perceived as warranting more than a yes/no response, when doctors did not sufficiently specify the terms of a question, and where double or multiple questions were posed at the same time.

These findings suggest that doctors who are unwilling (or who have not been trained) to use the 'EpiLing' interview method (or another semi-standardised approach) may be able to optimise responses by modifying the questions they pose to patients about attacks. For example, by clearly formulating questions and using more open-ended questions when they take the history.

A possible focus for future studies would be to compare one-to-one doctor-seizure patient interactions in which the 'EpiLing' interview method was used, with those in which doctors used their 'routine' communication style. This would now be possible as a number of one-to-one doctor-seizure patient interactions were collected during the course of this research project in which doctors (who had not previously used the 'EpiLing' interview method) used their 'usual' communication styles. Findings from these analyses would help establish if, in what ways, and to what extent, the 'EpiLing' interview method helps to elicit the differential features of seizure patient talk to a greater extent than more conventional consultation styles or methods. If doctors do not elect to use a formal 'EpiLing' interview method, which may prove too time consuming for use in an outpatient (seizure) clinic, findings could be used to help guide future recommendations to improve doctors 'interviewing' styles when they talk to patients about seizures.

The findings from the analysis presented in chapters five and six also indicate that the structure of accompanied interactions in this clinical setting, and how companions are involved in these encounters, warrants consideration.

It is important that seizure witnesses remain involved in (and are actively encouraged to attend) consultations in seizure clinics. There may be aspects of seizures that are within the epistemic domain of seizure-witnesses, and not available to patients; or can only be communicated by the patient through third party accounts. In addition, companions have been observed to provide additional, valuable information that may not have emerged in their absence in other clinical settings (Cordella, 2011 and Clayman et al, 2005). It is not surprising then that national guidelines and research conclude that witness accounts of attacks can be crucial for correct diagnosis (Leach et al, 2005; Smith, Dafalla and Chadwick, 1999 and Chowdhury, Nashef and Elwes, 2008).

However, in relation to identifying the differential features of seizure patient talk, the effects of companionship have been shown to have both negative and positive consequences. Opportunities for patients to describe their seizure experiences are likely to be reduced when a companion accompanies them. In addition, the contributions of seizure-witnesses (and doctors) may limit, obscure or influence patients' accounts. On the other hand, there are diagnostic pointers in the interactions between patients and companions (and of doctors and companions) that may help doctors differentiate between patients with epilepsy and PNES.

Consequently, the benefits and drawbacks of including companions in initial (routine) outpatient encounters between doctors and seizure patients, and how companions are included in these interactions, needs to be considered. Moreover, doctors using the 'EpiLing' interview method (or other semi-standardised 'interview' method) to take the history need to think particularly carefully about how they structure interactions when patients are accompanied. Whilst the 'EpiLing' interview method gives patients the time and space to describe what they have experienced, without a predetermined structure doctors using the 'EpiLing' interview method may find that companions interpret facets of seizure patient talk (for example, patient resistance, and formulation effort - such as pauses, hesitations and restarts) as opportunities to become involved in the conversation in ways that might detract from patients accounts.

Clinic time in the UK is pressured, and as Boyd and Heritage (2006) have observed, from the doctor's perspective, the goal of history-taking is to find out as much relevant information as quickly and efficiently as possible. If more time needs to be taken from consultations for eyewitness talk (which can often be crucial for diagnosis), then this is likely to come out of what the eyewitness talk most naturally replaces, i.e. time spent interrogating and evaluating patients' seizure accounts. This may mean that in initial (diagnostic) consultations, doctors may be less likely to examine patient's accounts in detail if eyewitnesses are present waiting to tell the doctor what they have seen.

Certainly in the accompanied data examined here, it was sometimes the case that companions intervened in patients accounts, and despite some attempts by doctors to redirect the conversation back to the patient, this technique did not always work in the data. In some instances the doctor did not appear to try and

redirect the conversation in the patient's favour until after the companion had described what they had witnessed or had 'conceded the floor'. This sometimes meant that companions described what they had witnessed before the patient had the opportunity to describe their experiences – if the patient subsequently did so.

However, if the diagnostically differential interactional, topical and linguistic features of seizure patient talk are to be assessed and used as part of doctors' diagnostic decision making processes, this clearly requires that patients are given opportunities to describe their experiences. Ensuring patients have the opportunity to describe what they have experienced, and companions have the opportunity to describe what they have witnessed is also of additional clinical importance. Differences in the factual content of patients' and witnesses' accounts have been observed (Reuber et al, 2011), and national guidelines suggest that witnesses may need educating to accurately describe their observations (NICE, 2012). To this end, doctors have been advised to take note of the source of information they use in their diagnostic considerations (Reuber et al, 2011).

In order to optimise the diagnostic potential of information doctors can obtain from patients themselves and from seizure witnesses it is suggested that doctors consider purposefully structuring initial (diagnostic) consultations when a companion is present. This follows Laidsaar-Powel and colleagues (2013) recommendations. In order to overcome the challenges associated with companion involvement in other clinical settings, the authors suggest, "*explicit clarification and agreement of preferred companion involvement levels and roles by the physician upon commencement of the consultation*" (p10).

Predefining a consultation structure and eliciting separate patient and seizure-witness accounts, and accounts in which both the patient and companion are involved, may help doctors to make better use of the differential features of seizure patient talk in their diagnostic considerations when patients are accompanied to seizure clinic visits.

The research presented in this thesis suggests that patients should be encouraged to describe their seizure experience (or perhaps at least one experience) before companions have the opportunity to describe what they

have witnessed. Moreover, doctors' contributions (and the potential influence of these) should be minimised during these (opening) accounts, and doctors should consider using more open-ended questions in order for patients to be able to set the initial agenda of the interaction.

One approach might be to encourage doctors to use the 'EpiLing' interview method (or one resembling it) during the early phase of the consultation. This might mean, for example, that the doctor initially asks the patient about their expectations of the visit or they pose another question that does not make mention of the complaint (e.g., "how can I help you?"). Following this, the doctor could ask the patient to describe a particular seizure experience (e.g. their first, worst or most recent seizure). This may be particularly appropriate given that authors have previously suggested that more differential topical, linguistic and interactive features are identified in the initial ('open') phases of seizure-patient consultations (Schwabe, Howell and Reuber, 2007). Moreover, such an approach could help ensure that there is a phase of the consultation in which the differential interactive, linguistic and topical features of seizure patient talk identified in previous research are less likely to be minimised, obscured or influenced by companion or doctor involvement.

It was previously suggested (in chapter five) that doctors could ask patients whether they would be happy to be interviewed on their own first, before the accompanying person is asked to join the discussion. This approach has been identified as preferable by authors in the past (especially those exploring interactions with adolescents and their parents) (van Staa, 2011).

However, given the positive influence of companions in other clinical settings (as described in chapter four), it may be preferable that companions are present for the duration of consultations. For example, companions in other clinical settings have been observed to raise topics, and prompt patients to discuss topics, not previously mentioned by the doctor or patient (Clayman et al, 2005 and Cordella, 2009). Indeed, this was often observed to be the case in the data examined here. Therefore, another approach would be to actively restrict accompanying persons contributions (in the early part of encounters) by doctors explicitly stating that they would like to talk to the patient initially and hear from the accompanying person at a later part of the encounter. If the companion is given the opportunity to listen to the patient's account, they may be able

subsequently to prompt the discussion of features, or add details not previously discussed by the patient (for example, in relation to periods of reduced consciousness and unconsciousness). Patients involved in these encounters may also prefer this approach - although this should be at the patient's discretion.

In order that doctors can make use of the potential diagnostic pointers in interactions involving patients and companions, a later phase of the consultation could be earmarked as an 'open' discussion; in which patients and companions are freely involved. For example, after the patient has described their expectations of the visit (or has responded to another open question) and a specific (e.g. their first or most recent seizure) or typical seizure experience, and the companion has had the opportunity to describe what they witnessed during that (another, or a typical) event, the patient-party could be encouraged to discuss another seizure episode. Displays of emotional support have been frequently cited as one of the most common companion roles in clinical encounters (e.g., Cordella, 2011; Ellingson, 2002, Labrecque et al, 2001 and Ishikawa et al, 2005a). To encourage shared involvement in a (joint) 'story telling' phase (and to elicit potential diagnostic pointers between the interactions of patients and companions), one approach may be to ask the patient-party to discuss what could be considered a particularly emotive event, for example, the patient's worst seizure episode.

It could also be the case that potential diagnostic pointers between the interactions of patients and companions are observed in other phases of the consultations not examined here, for example, diagnosis and treatment recommendation phases. In other clinical settings, companions have been found to be particularly active in discussions centred on diagnostic testing (Eggly et al, 2006), health management (including medication) (Ellingson, 2002; Tsai, 2000 and Gilliam et al, 2009), mental health (Ellingson, 2002), and family contexts (including, hereditary factors, marital status and family living arrangements) (Tsai, 2000). Examination of these discussions may yield additional conversational diagnostic pointers between participants (particularly, patients and companions) in these interactions.

7. Conclusion

It is evident that the potential (purposeful) structure of interactions where patients are accompanied by a companion, and the history-taking methods and styles used by doctors in these encounters, need to be explored in more depth in future studies. However, the exploratory research in this thesis has gone a considerable way to providing a foundation for future research.

In addition, this project has identified additional differential diagnostic pointers in relation to third parties, and the interactions between patients, companions and doctors in this clinical setting: the diagnostic value of which can now be examined in future studies (for instance in larger studies, with analysts blinded to patients' medical diagnosis). The findings from this thesis represent a significant step forward in our understanding of the differential potential of how people with seizures reference those not present when they talk to a doctor about their episodes, how they experience and cope with a seizure condition, and the effects of companions in the interaction between patients and doctors in this clinical setting.

Appendix

Figure 1: Diagnostic Scoring Aid communication guideline.

Adapted from Reuber, et al (2009). Using interactional and linguistic analysis to distinguish between epileptic and psychogenic nonepileptic seizures:
A prospective, blinded multirater study. *Epilepsy & Behavior*, 16(1), 139-144.

Scores for all items:

1 = in favour of epilepsy.

0 = unable to determine or rate.

-1 = in favour of PNES.

Section A. Interactional features

1. General focus on seizure experience

Observation	Score
Introduced by patient	1
Introduced by interviewer, followed by patient	0
Introduced by interviewer, lost by patient	-1

Guide This item (1) assesses whether it is the patient or the interviewer who initially directs the focus of the interview to the description of the seizure experience. Patients with epilepsy typically volunteer the description of subjective seizure symptoms early in the 'open phase' of the interview, while patients with PNES may express a desire to find out what is causing the seizures, describe the circumstances in which seizures occur and their effects on their lives, etc., without describing the seizure experience as such. Patients who direct the focus away from the seizure experience despite direction by the interviewer are more likely to be patients with PNES than patients with epilepsy.

2. Description of subjective seizure symptoms

Observation	Score
Volunteered	1
Offered when prompted	0
Prompting unanswered	-1

Guide This item (2) assesses whether the patient maintains the focus on the seizure experience – rather than causes, effects, circumstances, possible cures etc. – voluntarily throughout the interview, or whether the interviewer needs to direct the patient. Typically patients with epilepsy volunteer descriptions of subjective seizure symptoms – pre-ictal, ictal and post-ictal – throughout, while patients with PNES need prompting. If prompting goes unanswered, e.g. 'I don't know' without elaboration, the patient is more likely to be one with PNES than one with epilepsy.

3. Description of attempts at seizure suppression

Observation	Score
Volunteered	1
Not described/only on prompting	0
Prompting unanswered	-1

Guide This item (3) assesses whether the patient offers any description of attempted suppression of the seizure or seizure symptoms. Patients with epilepsy often attempt to suppress or control seizures and may volunteer descriptions of attempts or offer them when prompted. Both patients with epilepsy and patients with PNES may deny having the ability to suppress seizures. If prompting goes unanswered, e.g. 'I don't know' without elaboration, the patient is more likely to be one with PNES than one with epilepsy.

4. Description of phases of reduced self-control ('gaps')

Observation	Score
Volunteered	1
Offered when prompted	0
Prompting unanswered, 'holistic' statements only	-1

Guide This item (4) assesses whether the patient volunteers the description of periods of unconsciousness or lack of physical control – or 'gaps', or whether the interviewer directs the patient to this. 'Description' here refers to attempts at establishing contours of 'gaps', distinguishing multiple levels of consciousness/control, reconstructing events that took place during 'gaps', etc., rather than brief, holistic statements, e.g. 'I just go' or 'I black out'. Patients with epilepsy typically volunteer descriptions or offer them when prompted, while patients with PNES may not elaborate beyond holistic statements.

5. Response to challenge of accounts of phases of reduced self-control ('gaps')

Observation	Score
Elaboration or reformulation of previous description	1
Repeat or minimal elaboration	0
No prior description/no elaboration	-1

Guide This item (5) assesses how the patient responds to a challenge by the interviewer of a prior account of phases of reduced self-control. The interviewer may question aspects of the account, or invite a more detailed account with inquiries such as 'Is there anything which happens during your seizures which you can remember?', 'Can you communicate in any way during your seizures?', 'Can you indicate to people that you are going to have a seizure?', 'Is there a moment in your seizures where you can hear people but you cannot respond to them?', etc. Patients with epilepsy typically respond by elaborating on or otherwise reformulating the prior account. Both patients with epilepsy and patients with PNES may have offered a detailed description, volunteered or prompted, and repeat this after the challenge. Patients who fail to offer a description at all, even after challenge of prior holistic statements, are more likely to be patients with NES than patients with epilepsy.

6. Description of individual seizure episodes

Observation	Score
Volunteered	1
Not offered / episodes explicitly not distinguishable	0
Not offered, no explicit denial of ability to distinguish episodes	-1

Guide This item (6) assesses whether the patient volunteers the description of individual seizure episodes, or whether the interviewer directs the patient to this. 'Description' here refers to accounts that incorporate subjective seizure symptoms, rather than brief mentions of circumstances in which a seizure took place. Patients with epilepsy typically volunteer descriptions of individual seizure episodes or offer them when prompted. Both patients with epilepsy and patients with PNES may indicate that all seizures are the same. Patients who fail to provide a coherent description of an individual seizure episode despite prompting – that is, patients who show 'focussing resistance' – are more likely to be patients with PNES than patients with epilepsy.

Section B. Topical features

7. Subjective seizure symptoms

Observation	Score
Described in great detail	1
Little or some detail	0
(Listed but) not described in detail	-1

Guide This item (7) assesses the overall level of detail of the patient's description of subjective seizure symptoms. Detailed descriptions incorporate precise characterisations of pre-ictal, ictal and post-ictal experiences in individual or typical seizure episodes, drawing on own recollections as well as witness accounts. They establish a clear and coherent picture of the patient's seizure experience. Patients with epilepsy typically offer detailed descriptions of subjective seizure symptoms, while patients with PNES may leave the interviewer with little more than a vague idea of what constitutes their seizure experience. Patients who offer no description beyond brief statements, e.g. 'I feel dizzy', or 'I have a headache' without elaboration, are more likely to be patients with PNES than patients with epilepsy.

8. Relative importance of subjective seizure symptoms

Observation	Score
Treated as central to description	1
More or equal attention to circumstantial details	0
Not described beyond brief statements	-1

Guide This item (8) assesses the prominence of subjective seizure symptoms in the patient's description of individual or typical seizure episodes. Patients with epilepsy typically treat subjective seizure symptoms as central. Patients with PNES may provide a great deal of detail concerning the circumstances in which seizures have taken place – e.g. where they were, what time it was, what they were wearing, what happened before the seizure episode, etc. – while not

describing subjective seizure symptoms in as much detail. Patients who do not describe subjective seizure symptoms at all in accounts of individual or typical episodes are more likely to be patients with PNES than patients with epilepsy.

9. Phases of reduced self-control ('gaps')

Observation	Score
Described as one of several elements in the experience of seizure episodes	1
Described as a prominent element in the experience of seizure episodes	0
Described as the defining element of the seizures	-1

Guide This item (9) assesses the overall prominence of 'gaps' in the patient's description of the seizure experience. Patients with PNES typically present unconsciousness as the defining element of the seizures. Patients with epilepsy are more likely to discuss multiple pre-ictal, ictal and post-ictal symptoms and describe attempts to suppress seizures, thereby making the 'gap' a less prominent element in the description of the seizure experience.

10. Contouring of 'gaps' in seizure trajectory

Observation	Score
Considerable attempt to contour 'gaps' based on own recollections	1
Some attempt to contour 'gaps' based on own recollections	0
No coherent account of the seizure trajectory, or gaps contoured only on the basis of witness accounts	-1

Guide This item (10) assesses the extent to which the patient attempts to 'contour' 'gaps' in descriptions of individual seizure episodes. Patients with epilepsy typically attempt to place the 'gap' precisely in a sequence of events, possibly with an estimation of its duration based on recollections of events before and after. Both patients with epilepsy and patients with PNES may draw on witness accounts in contouring 'gaps'. Patients who rely entirely on witness accounts or fail to offer a coherent account of an individual seizure trajectory are more likely to be patients with PNES than patients with epilepsy.

11. Reconstruction of 'gaps'

Observation	Score
Considerable attempts to reconstruct events during 'gaps' based on own recollections	1
Some attempt to reconstruct events during 'gaps' based on own recollections	0
Displaying no willingness to reconstruct events during 'gaps' based on own recollections	-1

Guide This item (11) assesses the extent to which the patient displays a willingness to reconstruct events that took place during 'gaps' in consciousness in individual seizure episodes. Patients with epilepsy typically attempt to reconstruct events based on their own recollections of events before and after the 'gap'. Both patients with epilepsy and patients with PNES may draw on witness accounts. Patients who rely entirely on witness accounts or make no attempts to

reconstruct events at all are more likely to be patients with PNES than patients with epilepsy.

Section C. Linguistic features

12. Description of subjective seizure symptoms

Observation	Score
With marked formulation effort	1
With some / little formulation effort	0
No description beyond brief statements	-1

Guide This item (12) assesses the extent to which the patient displays active formulation effort in describing subjective seizure symptoms. Evidence of formulation effort includes the use of reformulations, hesitations, restarts and other ‘self-repair’ strategies, of metadiscursive comments that highlight both the difficulty of the task of describing and active effort to perform it, e.g. ‘how can I describe it’, and of understanding checks directed at the interviewer, e.g. ‘does that make sense?’. Patients with epilepsy typically display a high degree of formulation effort in describing subjective seizure symptoms, while patients with PNES may offer accounts which lack the features mentioned above. Patients who offer no description beyond brief statements, e.g. ‘I feel dizzy’, or ‘I have a headache’ without elaboration, are more likely to be patients with PNES than patients with epilepsy.

13. Negations in description of seizure experience

Observation	Score
With contextualised negations only	1
With some absolute negations	0
With pervasive absolute negations	-1

Guide This item (13) assesses the extent to which the patient describes the seizure experience using negative lexical items or grammatical constructions. Patients with epilepsy typically use negative items or constructions to refer to particular seizure symptoms, e.g. lack of consciousness, embedded in a description of the seizure experience in which negation is not pervasive. Such negations are called ‘contextualised’: e.g. ‘I’ve realised that I talk during my seizures, but I can never remember what I said afterwards’. Patients with PNES typically use negative items or constructions to suggest that they do not know anything about their seizures and can offer no relevant information to the interviewer. Such negations are called ‘absolute’: e.g. ‘I never remember anything about my seizures’ without elaboration. In other words, patients with epilepsy typically describe the seizure experience in terms of what they feel and remember, while patients with PNES may describe the seizure experience entirely in terms of what they *don’t* feel or remember.

14. Formulation effort associated with description of 'gaps'

Observation	Score
With marked formulation effort	1
With some/little formulation effort	0
No description beyond 'holistic' statements	-1

Guide This item (14) assesses the extent to which the patient displays active formulation effort in describing phases of reduced self-control – or 'gaps'. Again, evidence of formulation effort includes the use of reformulations, hesitations, restarts and other 'self-repair' strategies, of metadiscursive comments that highlight both the difficulty of the task of describing and active effort to perform it, e.g. 'how can I describe it', and of understanding checks directed at the interviewer, e.g. 'does that make sense?'. Patients with epilepsy typically display a high degree of formulation effort in describing 'gaps' in seizure episodes – that is, in attempting to establish contours of 'gaps', to distinguish multiple levels of consciousness/control, to reconstruct events that took place during 'gaps', etc., while patients with PNES may offer accounts which lack the features mentioned above. Patients who offer no description beyond brief, holistic statements, e.g. 'I just go' or 'I black out' without elaboration, are more likely to be patients with NES than patients with epilepsy.

15. Metaphoric conceptualisation of seizures

Observation	Score
Consistent across seizure descriptions	1
With some variation across seizure descriptions	0
No coherent conceptualisation	-1

Guide This item (15) assesses the extent to which the patient's overall seizure description displays a coherent metaphoric conceptualisation of the seizure experience. Patients with epilepsy typically offer multiple seizure descriptions in which the conceptualisation of the seizure experience is similar: e.g. the seizure is consistently characterised as a threatening entity which acts independently of the patient's will. Patients with PNES may show more variation in the conceptualisation across seizure descriptions. Patients whose descriptions do not display a coherent conceptualisation of the seizure experience are more likely to be patients with PNES than patients with epilepsy.

16. External / internal conceptualisation of seizures

Observation	Score
Seizures repeatedly conceptualised in terms of an external and/or threatening entity	1
Seizures sometimes conceptualised in terms of an external and/or threatening entity	0
Seizures not conceptualised in terms of an external and/or threatening entity	-1

Guide This item (16) assesses the extent to which the patient conceptualises the seizure as an external and/or threatening entity. Patients with epilepsy typically conceptualise the seizure as a threatening entity which acts independently of the patient's will. Patients who do not conceptualise the seizure in this way are more likely to be patients with PNES than patients with epilepsy.

17. Conceptualisation of seizures as a fight or struggle

Observation	Score
Seizures repeatedly conceptualised in terms of a fight or struggle	1
Seizures sometimes conceptualised in terms of a fight or struggle	0
Seizures not conceptualised in terms of a fight or struggle	-1

Guide This item (17) assesses the extent to which the patient conceptualises the seizure in terms of a fight or struggle. Patients with epilepsy typically describe attempts to suppress seizures or seizure symptoms using metaphors of fighting and struggling an external entity. Patients who do not describe attempts at seizure suppression and do not conceptualise the seizure in terms of a fight or struggle are more likely to be patients with PNES than patients with epilepsy.

Table 1: DSA item summary: item descriptions, observations and associated scores, and the significance of correct classification of items for each rater (adapted from Reuber et al, 2009).

Interactional features

Item	Description	Observation	Score	Significance of correct classification*	
				Rater 1	Rater 2
1	General focus on seizure experience (<i>rather than seizure situations or consequences</i>)	Introduced by P	1	0.037	n.s.
		Introduced by I, followed by P	0		
		Introduced by I, lost by P	-1		
2	Description of subjective seizure symptoms	Volunteered	1	n.s.	0.019
		Offered only when prompted	0		
		Prompting unanswered	-1		
3	Description of seizure suppression attempts	Volunteered	1	n.s.	n.s.
		Not described/only on prompting	0		
		Prompting unanswered	-1		
4	Description of 'gaps' (<i>phases of reduced self-control or recollection</i>)	Volunteered	1	n.s.	0.007
		Offered when prompted	0		
		Prompting unanswered/'holistic' statements only	-1		
5	Response to challenge of statements about 'gaps'	Elaboration or reformulation of previous description	1	n.s.	n.s.
		Repeat or minimal elaboration	0		
		No prior description/no elaboration	-1		
6	Description of individual seizure episodes (<i>possible 'focussing resistance': interactional resistance to focus on particular seizures</i>)	Volunteered	1	n.s.	0.041
		Not offered / episodes explicitly not distinguishable	0		
		Not offered, no explicit denial of ability to distinguish episodes	-1		

Observation: P = Patient

I = Interviewer

'Holistic': broad statements lacking detail, e.g. "I just go", "I'm out".

Statistics:

*Chi-square (χ^2) test of significance (p)

n.s. = not significant (p>0.05)

Score:

1 = in favour of epilepsy

0 =unable to determine or rate

-1 = in favour of PNES

Topical features.

Item	Description	Observation	Score	Significance of correct classification *	
				Rater 1	Rater 2
7	Subjective seizure symptoms	Described in great detail	1	0.038	n.s.
		Little or some detail	0		
		(Listed but) not described in detail	-1		
8	Relative importance of subjective seizure symptoms	Treated as central to description	1	0.035	0.038
		More or equal attention to circumstantial details	0		
		Not described beyond brief statements	-1		
9	Relative importance of 'gaps' (<i>phases of reduced self-control or recollection</i>)	One of several elements of seizures	1	0.008	0.008
		Prominent element of seizure episodes	0		
		Defining element of seizures	-1		
10	Contouring of 'gaps' in seizure trajectory (<i>eg. detailing of last memory before / first after seizure</i>)	Clear attempt to contour 'gaps'	1	0.05	0.024
		Some attempt to contour 'gaps'	0		
		No contouring of gaps / no clear seizure trajectory	-1		
11	Reconstruction of 'gaps' (<i>eg. filling own memory gaps with own recollections / witness accounts</i>)	Clear attempts to fill 'gaps' with own recollections	1	n.s.	n.s.
		Some attempts to reconstruct 'gaps' with own recollections	0		
		No attempts to reconstruct gaps using own recollections	-1		

Statistics:

*Chi-square (χ^2) test of significance (p)

n.s. = not significant (p>0.05)

Score:

1 = in favour of epilepsy

0 = unable to determine or rate

-1 = in favour of PNES

Linguistic features

Item	Description	Observation	Score	Significance of correct classification *	
				Rater 1	Rater 2
12	'Formulation effort' associated with description of subjective seizure symptoms (<i>'formulation effort' includes restarts, reformulations, neologisms</i>)	With marked formulation effort	1	0.011	n.s.
		With some / little formulation effort	0		
		No description beyond brief statements	-1		
13	Negations in descriptions of seizure experience (<i>absolute: 'I don't remember anything, contextualised: I remember X but not Y'</i>)	Contextualised negations only	1	n.s.	n.s.
		With some absolute negations	0		
		With pervasive absolute negations	-1		
14	'Formulation effort' associated with description of 'gaps'	With marked formulation effort	1	n.s.	n.s.
		With some/little formulation effort	0		
		No description beyond 'holistic' statements	-1		
15	Metaphoric seizure conceptualisation	Consistent across seizures	1	0.009	<0.001
		With variations across seizures	0		
		No coherent conceptualisation	-1		
16	External / internal conceptualisation of seizures	Consistent seizure conceptualisation as external	1	0.002	0.03
		Seizures sometimes conceptualised as external	0		
		Seizures not conceptualised as external	-1		
17	Conceptualisation of seizures as a fight / struggle	Seizures repeatedly conceptualised as a fight / struggle	1	n.s.	n.s.
		Seizures sometimes conceptualised as a fight / struggle	0		
		Seizures not conceptualised as a fight / struggle	-1		

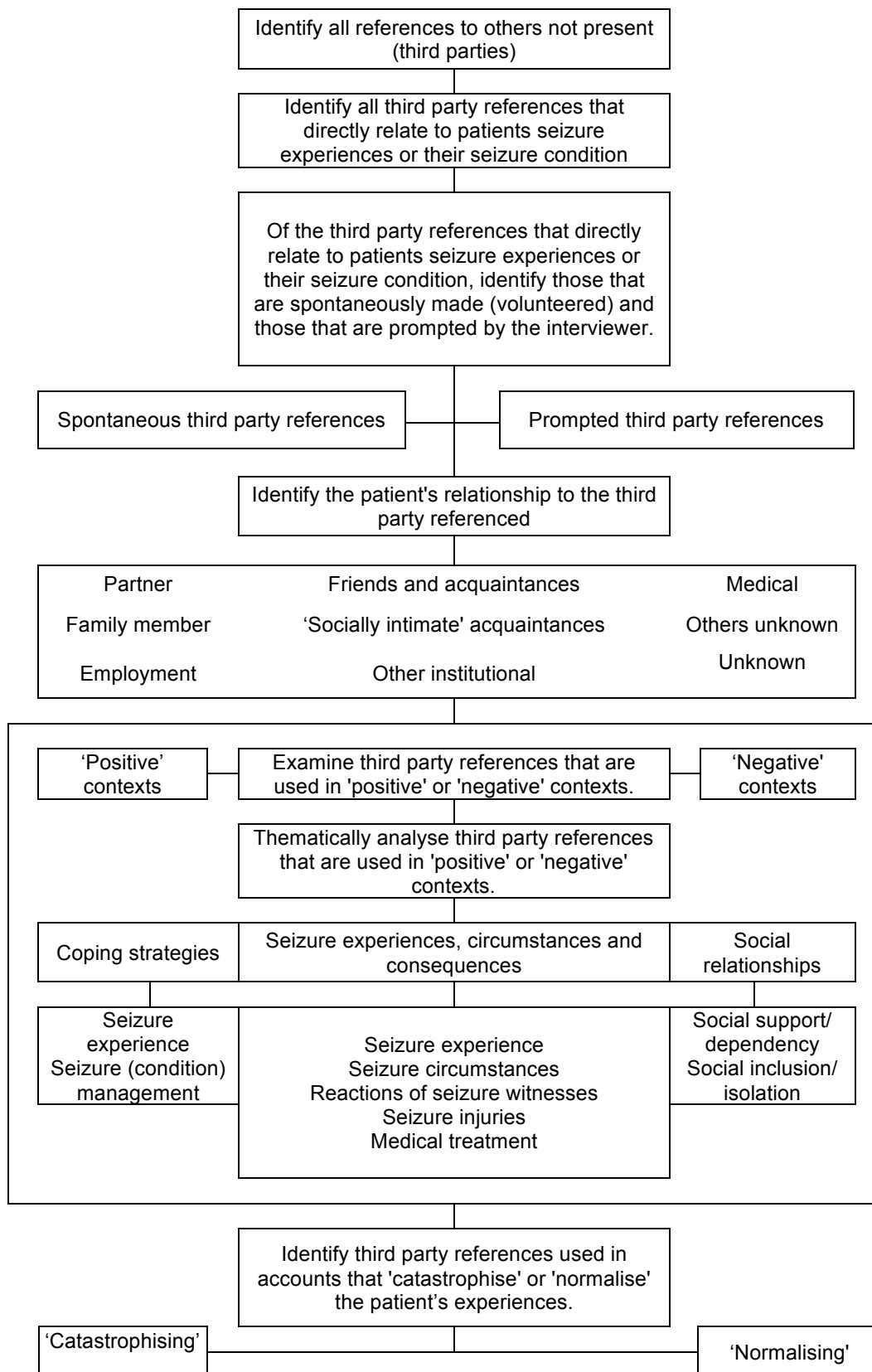
Statistics:
Score:

*Chi-square (χ^2) test of significance (p)
1 = in favour of epilepsy

n.s. = not significant (p>0.05)
0 =unable to determine or rate

-1 = in favour of PNE

Figure 2: Coding frame development flow chart



Extract 1.

An example of a patient with PNES (Laura) that referenced an ‘unknown’ ‘seizure-related third party’ (“dogs”, line 202 and 203) is presented below.

202 P: (0.9) or like (1.3) me dogs,
203 I had to feed me dogs (0.9) I were in d middle of
204 feeding em, (-) but I just left the food on d side,
205 ah I’d had a seizure, and left the food on d side.
206 (0.4) I set d CHIP pan on fire; (1.0) through
207 having one; (-) put (--) chips in (0.4)
208 (didn’t know how long) that chip pan had been on,
209 just put chips in an chip pan (went) up
210 in flames.
211 (0.6)

Extract 2.

An example of a patient with PNES (Barbara) that referenced an ‘other institutional’ ‘seizure-related third party’ (“police”, line 100, also referred to as “they” at line 97) is presented below.

88 D: Mmmm.
89 (1.2)
90 P: The only expectations I have is
91 that they give me (.) the best they can
92 and, I, I should imagine
93 they will.
94 (1.4)
95 P: So that’s it, I,
96 like I say, hhhh, I was on (.) that many
97 different pills that (.) they
98 D: (coughs)
99 P: found me) (1.2) wandering. I’d, I’d gone out,
100 obviously I was picked up by the police.

Extract 3.

An example of a ‘spontaneous seizure-related third party reference’ that was used during an account in which the patient ‘normalised’ their experience is presented below. The excerpt is taken from an interview with ‘Carl’ who has epilepsy. In the extract, Carl described that he has experienced absences whilst playing football that resulted in him going to hospital (see lines 1036 to 1039).

In spite of the fact that Carl described his seizures (absences) as “serious” (line 1036), Carl’s description appeared centred on why he did not feel (comparatively) worthy of medical attention. In this sense, Carl didn’t seem treat the problem

(seizure occurrences) as serious and the perceived or encountered 'dangers' (consequences) of seizures were minimised in his account.

For example, in reference to 'medical professionals, Carl described that "they're dealing with an area" (line 1043 to 1044). Carl appeared to position himself as outside of that "area". When he discussed why he had ended up in hospital, Carl described, "and I'm kicking a ball, and I ended up there" (line 1044 to 1045). In his account, Carl's reasons for ending up in hospital were more focused on the act of playing football than the fact he had experienced seizures, and the consequences of these. In the extract Carl made no mention of the physical consequences of the seizure episodes or the treatment he received in hospital as a result of them.

Carl completed his demonstration of normalisation when he explicitly referenced others that he perceived as worse off than himself, "I'm getting in the way of serious people that's injured" (lines 1045 to 1046). In doing so, Carl minimised the danger he encountered. He clearly did not consider himself a 'serious person that was injured', despite ending up in hospital as a result of the seizure episodes. The only emotional impact of seizures referenced in the account was that Carl felt that there were other people with more serious injuries, who were more deserving of medical attention, and that he felt, "very, felt very guilty about it" (line 1047).

- 1036 P: I've had two or three (0.9) serious,
1037 er (1.2), absences playing football,
1038 which have resulted in me going to the
1039 hospital, (0.6) and I've always been conscious
1040 of arriving in the hospital in
1041 football gear;
1042 D: Mh mh
1043 P: because I felt (0.6) if they're dealing with
1044 an area, (0.6) and I'm kicking a ball,
1045 and I ended up there, I'm getting in
1046 the way of serious people that's injured,
1047 and I was very, felt very guilty about it.
1048 D: Mh

Extract 4.

An example of how someone with PNES (Laura) used a 'spontaneous seizure-related third party reference' during an account in which she 'catastrophised' her experiences is presented below.

In the extract, the doctor questioned something Laura had previously (spontaneously) mentioned in the interview. At line 88, Laura described her seizures as "really scary". Returning to this comment, the doctor questioned whether Laura was "scared in the seizures?" (line 154) or whether she was "scared about the seizures?" (line 155). The doctor's question made no reference to third parties.

Laura's account was typified by her negative 'mental set', Laura described being "both scared" (line 157) "about" (lines 156, 158) the seizures, and "scared in" (line 158) the seizures. Laura reported being "scared when they happen" (line 183), "scared before they happen" (lines 183 to 184) and "scared altogether about them" (lines 184 to 185).

Laura used the word "scared" no less than twelve times in the extract presented below. Evidently, Laura has thought repeatedly and carefully about the extent that she felt "scared", and had ruminated on this feeling, which was magnified in her account.

In the account, Laura described that she has had ('major') seizures in which she has fallen, "I had one, I've had quite a few major ones, where I fell" (lines 160 to 161). Laura focused on one seizure in particular in which she fell out of her front door, "I had one where I fell out me front door", Laura went on to describe that she "hurt" (line 163) her ankle in the fall and that she continued to experience "pain" (line 165).

In her account, Laura emphasized the possibility that bad things could happen to her. Laura reported being scared of falling again, "what scares me whether I'm gonna fall again" (line 167). Moreover, that she may fall and seriously injure herself, "whether I'm gonna fall and seriously hurt meself" (lines 170 to 171).

Laura qualified this possibility by referencing a ('unknown other') third party, "cos I know people fall and really hurt themselves".

Similarly, Laura reported that she has already fallen down three stairs, "I fell down (three) stairs already" (lines 176 to 177), and had considered the possibility that she might fall 'from the top to the bottom', "I'm (--) scared of falling from top to bottom of d stairs" (lines 177 to 178).

Laura's described her fear of falling and injuring herself as making her scared of doing things, "that's why I'm scared of doing (things)" (line 173). Laura's communication of the extent to which she felt "scared" (for example, "I'm really scared", line 182) reflected her apparent inability (helplessness) to cope with her seizures and the potential consequences of these (the fear of falling).

- 154 D: Are you scared in the seizure? Or
155 are you scared about the seizures?
156 P: I'm scared about them,
157 (0.9) I'm so, I'm scared both,
158 I'm scared about them and scared in em.
159 (---) They do (.) they do really scare me,
160 because (---) I had one, I've had quite a few
161 major ones, where I fell (0.9).
162 I had one where I fell out me front door
163 (-) and I'd (hurt) me ankle, me ankle has never
164 been right since, (1.0) and (.) I just get,
165 I get a lot of pain in me ankle now,
166 since I had that seizure, (0.4) an that's
167 what scares me whether I'm gonna fall again.
168 (0.4)
169 D: Mh mh
170 P: Erm, whether I'm gonna fall and seriously
171 hurt meself (1.9) cos I know people fall
172 (and really) hurt themselves (aren't they?), so
173 and (-) that's why I'm scared of doing (things).
174 (0.4)
175 D: Mh
176 P: I, though, I fell down (three) stairs
177 already I'm (--) scared of falling from
178 top to bottom of d stairs and they are steep.
179 D: Mh,
180 P: They (ain't) got banister rails on, to stop me
181 from falling (1.4) so (---) but er (-).
182 No I am (0.4) I'm really scared (0.9),
183 scared when they happen, and I'm scared
184 before they happen, I'm scared
185 altogether about them.
186 (1.8)

Extract 5.

A 'seizure-related third party reference' to a 'partner', in which the patient neither 'catastrophised' nor 'normalised' their experience, is shown below. This was taken from a consultation with Jack, a patient with epilepsy. In the extract, Jack referred to his wife ("my wife", line 243), to his "not speaking much" in response to his wife (line 248 to 250), but then "talking nicely" to her (line 257) after his seizure experience (described in lines 250 to 255).

243 P: got me a bit and I think my wife got a
244 bit irritated, because she'd got a lot of stuff
245 at home that she should be doing
246 D: mh;
247 (1.5)
248 P: and I didn't do much speaking at that.
249 I went back home and hardly said anything
250 to her in the end (0.3). Clammed up again
251 (1.8) and (0.3) then on (1.2) Tuesday night
252 was when I started to get thee erm (1.9)
253 seizures. I knew, I knew nothing about it.
254 It started about ten o'clock in the morning
255 actually (1.1) and I knew nothing (0.9) nothing
256 about it. I woke up occasionally and I did
257 talk nicely and then I just went back
258 to sleep again.

Figure 3: Final coding frame

Code used	Definition	Notes on application	For an example of operationalization, see Chapter Three:
<p>‘Seizure and non-seizure third party reference’</p>	<p>Patients are identified as referencing a third party when they mentioned a family member, partner, friend, colleague, medic, passers-by, persons, or anyone – named or otherwise during their conversation with the doctor.</p>	<p>When patients introduce or re-introduce a third party into the conversation the third party is usually named or another identifying characteristic attached (for example, ‘my husband’). If the third party is referenced again in the course of the same topical discussion, patients usually use pronouns (for example, ‘he’ or ‘she’) or other identifiers (for example, ‘the customer’) to describe the third party.</p> <p>After a third party had been named or identified by the patient, subsequent pronouns (or other identifiers) used to reference the same third party are not counted if made in the bounds of the same topical discussion.</p> <p>Following the work of Rohde and Frank (2011), a topical discussion is defined as discourse consisting of an utterance or series of utterances centred on a shared topic. These topical discourse areas could be an utterance or sequences of utterances that transparently referred to the same object or topic. Or in less explicit cases, a sequence of utterances spanning a set of observations exchanged on the same topic.</p> <p>There is no requirement that the third party reference is made in the context of the patient discussing their seizure experiences or their seizure condition. That is, all references to third parties in the data are identified for inclusion in this category, regardless of the topical content of the discussion in which they are referenced.</p>	<p>Extract 3a</p>

<p>‘Seizure-related third party reference’</p>	<p>Patients are identified as referencing a ‘seizure-related third party’ when, in describing their seizure experiences or their seizure condition, they mentioned a family member, partner, friend, colleague, medic, passerby, persons, or anyone – named or otherwise.</p>	<p>The same criteria detailed immediately above are applied to this code. However, the topical content of the third party reference must contain discussion of the patient’s seizure experiences or their seizure condition for inclusion in this category. For example, ‘Seizure-related third party references’ are made when patients reference third parties that have witnessed attacks, those who may have witnessed the patient’s state, or those to whom the patient spoke in the aftermath of attacks. Third parties that are referenced when patients describe how they managed their seizures, how they cope with the condition, the impact of having seizures on their day-to-day lives, and how they feel others perceive their condition are also included in this category.</p> <p>An example of a third party reference unconnected with any seizure experience or discussion of the patient’s seizure condition (and thus excluded from this category) is presented in chapter three, extract 3b.</p>	<p>Extract 3c</p>
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<p>‘Spontaneous seizure-related third party reference’</p>	<p>The ‘seizure-related third party reference’ is spontaneously made (volunteered) by the patient.</p>	<p>The criteria detailed for ‘Seizure-related third party references’ (above) are applied to this code. The interviewer (doctor) does not ask or prompt the patient to discuss a third party. The patient spontaneously volunteers a ‘seizure-related third party reference’.</p>	<p>Extract 3c</p>
<p>‘Prompted seizure-related third party reference’</p>	<p>The patient is prompted to discuss the ‘seizure-related third party reference’.</p>	<p>The criteria detailed for ‘Seizure-related third party references’ are applied to this code. The interviewer (doctor) specifically asks the patient to discuss/explore a third party reference and the patient references a ‘seizure-related third party’.</p> <p>If the patient was prompted to discuss a third party they had previously (spontaneously) referenced, the former was classified as a ‘spontaneous seizure-related third party reference’ and the latter was classified as a ‘prompted seizure-related third party reference’.</p> <p>After being prompted by the doctor to discuss a third party, the patient may refer to the third party using pronouns (for example, ‘he’, ‘she’, ‘they’).</p> <p>If patients referenced a third party after being prompted by the interviewer to do so and (for example) used a pronoun to do this (or any other identifier), this is considered a ‘prompted seizure-related third party reference’. If the patient uses subsequent pronouns (or other identifiers) to reference the same third party in the bounds of the same topical (‘seizure-related’) discussion, then these are not counted as (additional) third party references.</p>	<p>Extract 3d</p>

'Family member'	A member of the patient's family, excluding that of partner, (for example, son, daughter, mother, father, brother, sister, niece, nephew, cousin).	Using the 'seizure-related third party reference' criteria set forth above, the 'seizure-related third party reference' is identified and coded as belonging to one of the eight (mutually exclusive) categories in the column to the left.	Extract 3h.
'Partner'	The patient's partner (for example, spouse, girlfriend, boyfriend; past or present).		Extract 3c. Extract 3h. Extract 3i.
'Friends and acquaintances'	Someone the patient knows socially (for example, a friend or neighbour).		Extract 3g.
'Socially intimate acquaintances'	The sum total of 'partner', 'family member' and 'friends and acquaintances' references.		Not applicable.
'Unknown other'	Someone unknown to the patient (for example, 'someone helped me', 'a man approached me', 'I came round and a woman was standing over me').		Extract 3e. Extract 3j. Appendix, Extract 4.
'Medical'	A member of the medical profession (for example, doctor, nurse, psychiatrist, paramedic).		Appendix, Extract 3.
'Employment'	A work colleague, employer or customer in a place of work (for example, boss, colleague, assistant).		Extract 3a. Extract 3f.
'Other institutional'	A member of another institution, excluding 'medical' and 'employment' institutions, (for example, police men, firemen, dentists, teachers).		Appendix, Extract 2
'Unknown'	The third party reference could not be identified, or fell outside of other categories (for example, reference to a pet).		Appendix, Extract 1

'Catastrophising - seizure-related third party references'	<p>'Catastrophising - seizure-related third party references' are coded when, in describing their seizure experiences or their seizure condition, participants reference at least one 'seizure-related third party' and communicate a negative 'mental set' comprised of three correlating dimensions; 'magnification, rumination and helplessness' (Sullivan et al, 2001).</p>	<p>Patients sometimes use more than one 'seizure-related third party reference' to 'catastrophise or 'normalise' their experiences. To avoid 'over counting', it is stipulated that at least one 'seizure-related third party reference' is used in accounts that 'catastrophise' or 'normalise' the patient's experience. Additional (other) 'seizure-related third party references' used in the same 'catastrophising' or 'normalising' account are discarded (not counted). That is, if two or more 'seizure-related third party references' are used in the same 'catastrophising' or 'normalising' account, it is counted as a single display.</p> <p>Following this, if the doctor is not observed to prompt the patient to discuss a third party, and the patient spontaneously references a 'seizure-related third party' in the course of a 'catastrophising' or 'normalising' account, then this is regarded as a single 'Normalising - spontaneous - seizure-related third party reference' or a 'Catastrophising - spontaneous - seizure-related third party reference', regardless of the number of third parties referenced by the patient in the account in which they 'catastrophise' or 'normalise' their experience.</p> <p>Similarly, if the doctor is observed to prompt the patient to discuss a third party, and in responding to this request the patient uses a 'seizure-related third party reference' to 'catastrophise' or 'normalise' their experience, then this is regarded as a single 'Normalising – prompted - seizure-related third party reference' or a 'Catastrophising – prompted - seizure-related third party reference', regardless of the number of third parties referenced by the patient in the account in which they 'catastrophise' or 'normalise' their experience.</p>	<p>Extract 3i. Extract 3j. Appendix, extract 4</p>
'Catastrophising - spontaneous - seizure-related third party references'			
'Catastrophising – prompted - seizure-related third party references'			
'Normalising - seizure-related third party references'	<p>'Normalising - seizure-related third party references' are coded when, in describing their seizure experiences or their seizure condition, participants reference at least one 'seizure-related third party' and they express 'troubles resistance', 'down play', or seem not to treat the problem (for example, seizure occurrence) as serious, and minimise the perceived or encountered 'dangers' (consequences) of seizures or the emotional or social impact of having seizures in their account.</p>	<p>Similarly, if the doctor is observed to prompt the patient to discuss a third party, and in responding to this request the patient uses a 'seizure-related third party reference' to 'catastrophise' or 'normalise' their experience, then this is regarded as a single 'Normalising – prompted - seizure-related third party reference' or a 'Catastrophising – prompted - seizure-related third party reference', regardless of the number of third parties referenced by the patient in the account in which they 'catastrophise' or 'normalise' their experience.</p>	<p>Extract 3g. Extract 3h. Appendix, extract 3</p> <p>An example of a 'seizure-related third party reference' not used to 'catastrophise' or 'normalise' the patient's experience is presented in the Appendix, see extract 5.</p>
'Normalising - spontaneous - seizure-related third party references'			
'Normalising - prompted - seizure-related third party references'			

Figure 4: Flow chart summary of search procedure, inclusion and exclusion criteria, and the number of studies identified at each stage of the search

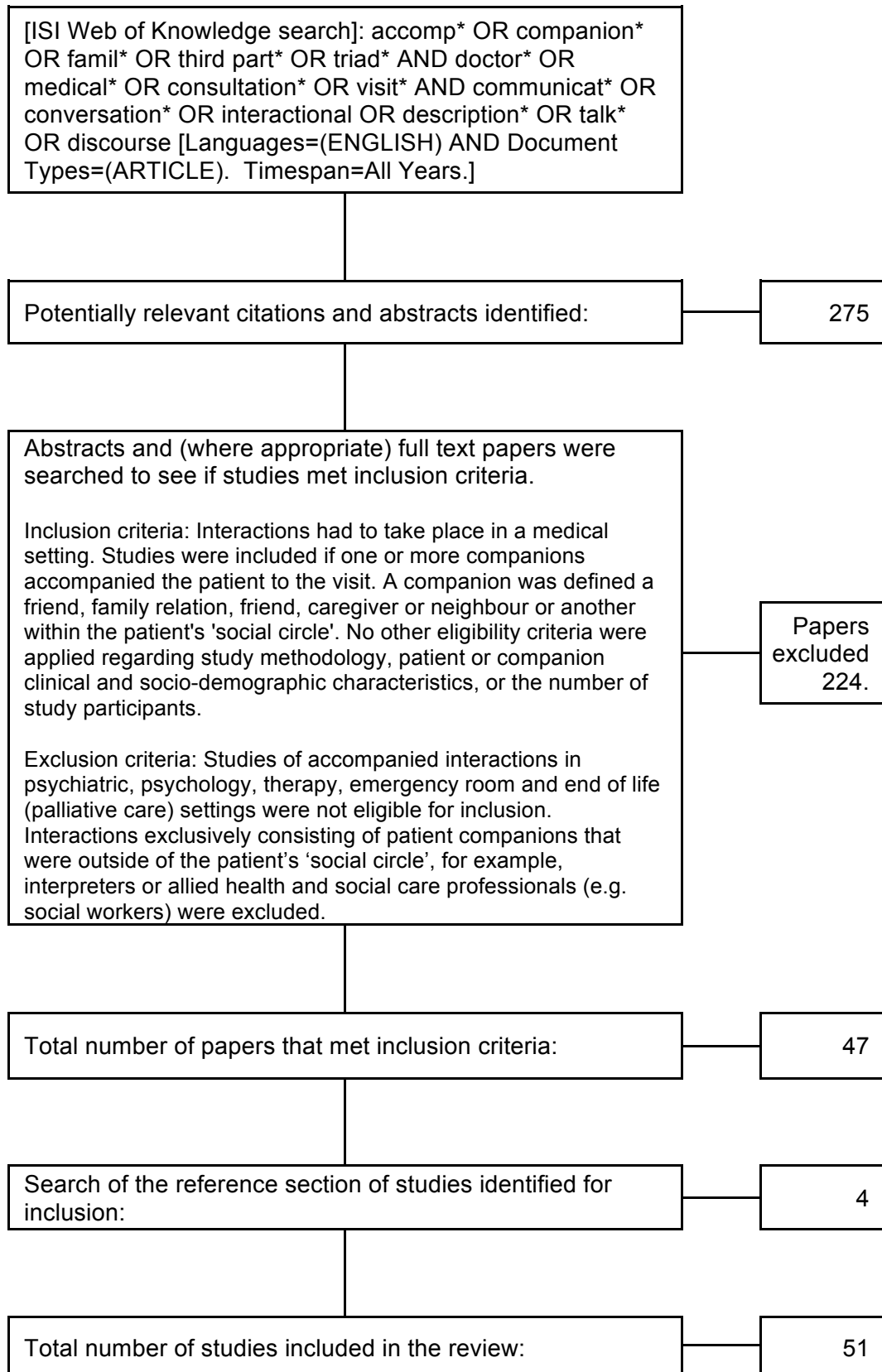


Figure 5. Number of studies included in each phase of the literature review analyses.

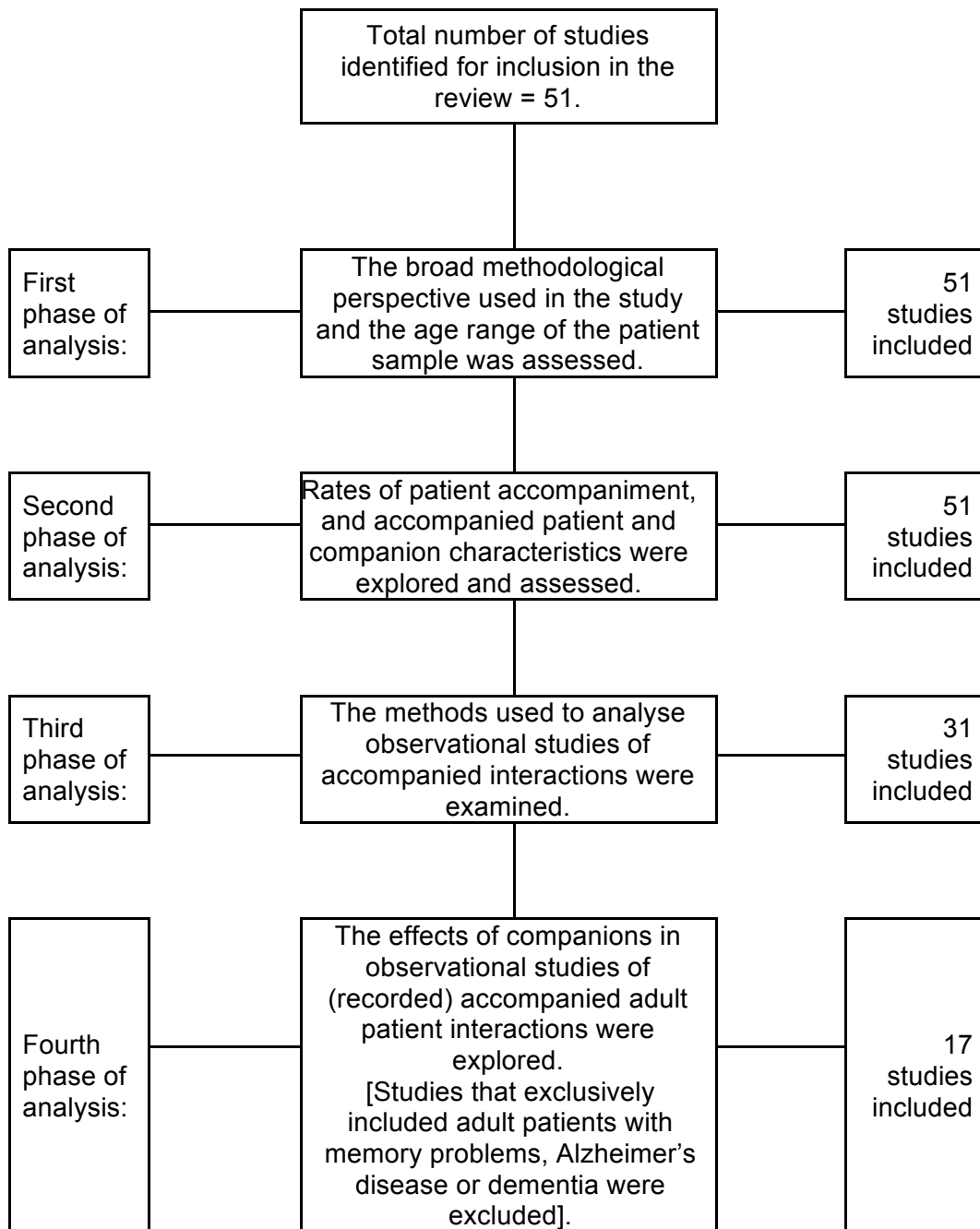


Table 2: Literature review summary – basic study information.

Used in phase of analysis:	Author(s) and Year	Patient sample (age group)	Number of participants (main sample)	Medical setting	Country	Methodology used	Main data collection method(s)
1 & 2	Adelman, Greene and Charon (1987)	Older adults	NA	NA	NA	Conceptual/theoretical framework	NA
1 & 2	Barone, Yoels and Clair (1999)	Patients of all ages	36 doctors	Specialist - hospital based - outpatient - Paediatric and Geriatric	US	Empirical - Quantitative	Interview
1 & 2	Beisecker (1996)	Older adults	Not stated	See description for details	NA	Literature review	Literature review
1 & 2	Beisecker and Moore (1994)	Adults (all ages)	12 doctors	Specialist - hospital based - outpatient - Oncology	US	Empirical - Qualitative	Interview
1 & 2	Beisecker et al (1997)	Adults (all ages)	35 participants	Specialist - hospital based - outpatient - Oncology	US	Empirical - Quantitative	Telephone interviews
1 & 2	Brown et al (1998)	Patients of all ages	8 doctors	General practice - community	Canada	Empirical - Quantitative	Survey
1 & 2	Cahill and Papageorgiou (2007a)	Children	21 studies	See description for details	NA	Literature review	Literature review
1 & 2	Fortinsky (2001)	Older adults	NA	NA	NA	Conceptual/theoretical framework	NA
1 & 2	Gabe et al (2004)	Children	NA	NA	NA	Conceptual/theoretical framework	NA

Used in phase of analysis:	Author(s) and Year	Patient sample (age group)	Number of participants (main sample)	Medical setting	Country	Methodology used	Main data collection method(s)
1 & 2	Glasser and Prohaska (1999)	Older adults	104 patients	General practice - community	US	Empirical - Quantitative	Survey
1 & 2	Glasser, Prohaska and Gravdal (2001)	Older adults	185 patients	General practice - community	US	Empirical - Quantitative	Survey
1 & 2	Hasselkus (1992)	Older adults	27 patients	Specialist - hospital based - outpatients - Geriatric and Medicine	US	Empirical - Qualitative	Non-participant observation
1 & 2	Main et al (2001)	Patients of all ages	1600 patients	General practice - community	US	Empirical - Mixed methods	Non-participant observation and interviews
1 & 2	Prohaska and Glasser (1996)	Older adults	136 patients	General practice - community	US	Empirical - Quantitative	Survey and interview
1 & 2	Rosland et al (2011)	Adults (all ages)	439 patients	General practice - community	US	Empirical - Quantitative	Survey
1 & 2	Schilling et al (2002)	Adults (all ages)	1294 patient visits, 378 survey	General practice - community	US	Empirical - Quantitative	Direct observation (waiting room) and survey methods.
1 & 2	Street and Millay (2001)	Adults (all ages)	NA	NA	NA	Conceptual/theoretical framework	NA
1 & 2	Tates and Meeuwesen (2001)	Children	12 studies	See description for details	NA	Literature review	Literature review

Used in phase of analysis:	Author(s) and Year	Patient sample (age group)	Number of participants (main sample)	Medical setting	Country	Methodology used	Main data collection method(s)
1 & 2	Wolff and Roter (2011)	Adults (all ages)	17 studies	See description for details	NA	Meta analysis	Literature review
1 & 2 & 3	Aronsson and Rundstrom (1988)	Children	32 patients	Specialist - hospital based - outpatients - paediatrics	Netherlands	Empirical - Mixed methods	Recorded medical encounters
1 & 2 & 3	Bindera et al (2010)	Children	665 patients	General practice - hospital based	France	Empirical - Quantitative	Recorded medical encounters and questionnaires
1 & 2 & 3	Buchbinder (2009)	Children	1 patient	Specialist - hospital based - outpatients	US	Empirical - Qualitative	Recorded medical encounters
1 & 2 & 3	Cahill and Papageorgiou (2007b)	Children	31 patients	General practice - community	UK	Empirical - Qualitative	Recorded medical encounters
1 & 2 & 3	Karnieli-Miller et al (2009)	Older adults	25 patients	Specialist - hospital based - outpatients - memory clinic	Israel	Empirical - Qualitative	Recorded medical encounters
1 & 2 & 3	Pantell et al (1982)	Children	115 patients	Specialist - hospital based - outpatients - Paediatrics	US	Empirical - Quantitative	Recorded medical encounters and questionnaires
1 & 2 & 3	Sakai et al (2011)	Older adults	86 patients	General practice - hospital based - Alzheimer's research centre	US	Empirical - Quantitative	Recorded medical encounters and questionnaires
1 & 2 & 3	Schmidt et al (2009)	Older adults	23 patients	General practice - hospital based - memory clinic	US	Empirical - Quantitative	Recorded medical encounters and questionnaires

Used in phase of analysis:	Author(s) and Year	Patient sample (age group)	Number of participants (main sample)	Medical setting	Country	Methodology used	Main data collection method(s)
1 & 2 & 3	Stivers (2001)	Children	100 patients	General practice - community and hospital based	US	Empirical - Qualitative	Recorded medical encounters
1 & 2 & 3	Tates and Meeuwesen (2000)	Children	105 patients	General practice - community	Netherlands	Empirical - Mixed methods	Recorded medical encounters
1 & 2 & 3	Tates et al (2002a)	Children	105 patients	General practice - community	Netherlands	Empirical - Mixed methods	Recorded medical encounters
1 & 2 & 3	Tates et al (2002b)	Children	106 patients	General practice - community	Netherlands	Empirical - Mixed methods	Recorded medical encounters
1 & 2 & 3	van Staa (2011)	Children	39 patients	Specialist - hospital based - outpatients - paediatrics	Netherlands	Empirical - Mixed methods	Interviews, focus groups, questionnaires, direct observation of encounters.
1 & 2 & 3	Wassmer et al (2004)	Children	51 patients	Specialist - hospital based - outpatients - paediatrics	UK	Empirical - Quantitative	Recorded medical encounters and questionnaires
1 & 2 & 3	Zaleta et al (2010)	Older adults	54 patients	General practice - hospital based - Alzheimer's research centre	US	Empirical - Quantitative	Recorded medical encounters
1 & 2 & 3 & 4	Beiseker (1989)	Older adults	21 patients	Specialist - hospital based - outpatient - physical medicine and rehabilitation	US	Empirical - Quantitative	Recorded medical encounters

Used in phase of analysis:	Author(s) and Year	Patient sample (age group)	Number of participants (main sample)	Medical setting	Country	Methodology used	Main data collection method(s)
1 & 2 & 3 & 4	Clayman et al (2005)	Older adults	93 patients	General practice - hospital based - geriatric	US	Empirical - Quantitative	Recorded medical encounters
1 & 2 & 3 & 4	Coe and Prendergast (1985)	Older adults	7 patients	General practice and specialist - hospital based - geriatric	US	Empirical - Qualitative	Recorded medical encounters
1 & 2 & 3 & 4	Cordella (2011)	Adults (all ages)	9 patients	Specialist - hospital based - outpatient - oncology	Chile	Empirical - Mixed methods	Recorded medical encounters
1 & 2 & 3 & 4	Eggy et al (2006)	Adults (all ages)	28 patients	Specialist - hospital based - outpatient - oncology	US	Empirical - Quantitative	Recorded medical encounters
1 & 2 & 3 & 4	Eggy et al (2011)	Adults (all ages)	109 patients	Specialist - hospital based - outpatient - oncology	US	Empirical - Quantitative	Recorded medical encounters
1 & 2 & 3 & 4	Ellingson (2002)	Older adults	9 patients	Specialist - hospital based - outpatients - geriatric oncology	US	Empirical - Qualitative	Recorded medical encounters and participant obsv.
1 & 2 & 3 & 4	Gilliam et al (2009)	Adults (all ages)	60 patients	Specialist - community - outpatient - neurology	US	Empirical - Qualitative	Recorded medical encounters
1 & 2 & 3 & 4	Greene et al (1994)	Older adults	30 patients	General practice - hospital based - geriatric	US	Empirical - Mixed methods	Recorded medical encounters and questionnaires
1 & 2 & 3 & 4	Ishikawa et al (2005a)	Older adults	145 patients	General practice - hospital based - geriatric	Japan	Empirical - Quantitative	Recorded medical encounters and questionnaires
1 & 2 & 3 & 4	Ishikawa et al (2005b)	Older adults	145 patients	General practice - hospital based - geriatric	Japan	Empirical - Quantitative	Recorded medical encounters and questionnaires

Used in phase of analysis:	Author(s) and Year	Patient sample (age group)	Number of participants (main sample)	Medical setting	Country	Methodology used	Main data collection method(s)
1 & 2 & 3 & 4	Labrecque et al (1991)	Adults (all ages)	473 patients	Specialist - hospital based - outpatient - oncology	US	Empirical - Quantitative	Recorded medical encounters and questionnaires
1 & 2 & 3 & 4	Oguchi et al (2010)	Older adults	51 patients	Specialist - hospital based - outpatient - oncology	Australia	Empirical - Quantitative	Recorded medical encounters
1 & 2 & 3 & 4	Shields et al (2005)	Older adults	30 patients	General practice - community and hospital based	US	Empirical - Quantitative	Recorded medical encounters and questionnaires
1 & 2 & 3 & 4	Street and Gordon (2008)	Adults (all ages)	132 patients	Specialist - hospital based - outpatient - oncology	US	Empirical - Quantitative	Recorded medical encounters and questionnaires
1 & 2 & 3 & 4	Tsai (2000)	Older adults	15 patients	General practice - hospital based - geriatric	Taiwan	Empirical - Mixed methods	Recorded medical encounters
1 & 2 & 3 & 4	Wolff and Roter (2012)	Older adults	390 patients	General practice - community	US	Empirical - Quantitative	Recorded medical encounters and questionnaires

Table 3: Literature review summary – study description, focus of the analysis, and summary of findings.

Used in phase of analysis:	Author(s) and Year	Description	Focus of analysis	Summary of findings / description of conceptual frameworks.
1 & 2	Adelman, Greene and Charon (1987)	The authors presented a conceptual framework for analysing triadic encounters: the Multi-dimensional Interactive system of Analysis (MDIA).	Application of the MDIA system as a means to analyse triadic encounters.	The different methods to analyse triadic encounters (broadly conceptualised as either process analysis methods or microanalytic methods), and the pros and cons of these, were discussed. The authors described how these methods are combined in the MDIA. The application of the MDIA and the benefits of using the MDIA were discussed.
1 & 2	Barone, Yoels and Clair (1999)	18 paediatric and 18 geriatric physicians drawn from a random sample were interviewed, face-to-face, using an in-depth, structured questionnaire. Interviews were recorded. Responses to open questions were transcribed and analysed using content analysis.	Rates of patient accompaniment and doctor-patient intimacy in accompanied visits.	Paediatricians estimated 96% of their patients were accompanied to visits, whereas geriatricians estimated 55% of their older patients were accompanied. Most companions were estimated to be female (72%). Geriatricians perceived the presence of a companion (accompanying person) as contributing to a loss of intimacy. Paediatrician's only perceived a loss of intimacy occurring with accompanied adolescent (as opposed to younger) patients.
1 & 2	Beisecker (1996)	The author examined accompanied older persons medical encounters and their outcomes using literature review methods. However, the specific methods by which the literature was reviewed are not detailed (for example, medical setting criteria).	Participant (patient and companion) characteristics were examined in terms of the content of the encounters, the context of the encounters, and patient outcomes.	In the paper there is a focus on the doctor-older patient relationship. However, the author observed that older patients are frequently accompanied (usually by a spouse or adult child) to medical visits, and the role of caregivers (companions) forms a major part of the discussion. The author suggests that the situation encountered (the context of the encounter, particularly in relation to reason for the visit and/or diagnosis) may be more important than the (socio-demographic) characteristics of the participants.

Used in phase of analysis:	Author(s) and Year	Description	Focus of analysis	Summary of findings / description of conceptual frameworks.
1 & 2	Beisecker and Moore (1994)	Semi structured interviews were conducted with 12 oncologists (6 medical, 4 surgical, and 2 radiation).	Doctor perceptions of the effects of companions.	Oncologists estimated that three-quarters of their cancer patients were regularly accompanied to appointments. Consultations in which companions were present were perceived as more complex. Young professional men and older women accompanying their husband were perceived as the most assertive companions and those that asked the most questions. Doctors reported that they typically observed all possible coalitions at least once during accompanied medical visits.
1 & 2	Beisecker et al (1997)	Structured telephone interviews (mainly comprised of likert scales) were conducted with 18 patients and 17 unmatched companions of cancer patients. Conversations were audio-recorded.	Rate of patient accompaniment, accompanied patient and companion characteristics, and how patients felt about companion presence.	Patients reported they were usually accompanied to visits, and that their companion was usually their spouse. When the primary companion was unavailable most patients (over 50%) reported they did not ask someone else to attend. Patients reported being more frequently accompanied to appointments at the beginning of treatments and when test results were to be discussed. Companions perceived themselves as more active (talked more) than patients perceived their companions to be (but note, pairs were not matched). Patients and companions rated providing support and companionship as the main reason for companion attendance (though this was higher in the companion group).

Used in phase of analysis:	Author(s) and Year	Description	Focus of analysis	Summary of findings / description of conceptual frameworks.
1 & 2	Brown et al (1998)	Eight family doctors completed 100 consecutive surveys, resulting in 783 cases available for analysis. Results were analysed using statistical methods.	Rates of patient accompaniment and accompanied patient and companion characteristics.	Nearly one third (30%) of patients were accompanied to visits, with children and elderly patients (over 75 years of age) significantly more likely to be accompanied. The companion was usually a parent, or spouse of the patient. Six different patient-accompanying person dyads were identified. 45.8% (109) of visits were made by children accompanied by parent(s), 24.4% (58) were adult's accompanied by their spouse's, 15.1% were parent's accompanied by a child, 10.5% (25) were child or adult patient's accompanied by a sibling, 3.8% (9) were senior patient's accompanied by adult children. Companions were most often female (72.6%). Patients that were accompanied were more likely to have acute problems compared to unaccompanied patients. Accompanied senior patients were more likely to present with a chronic condition (64.4%).
1 & 2	Cahill and Papageorgiou (2007a)	The authors presented a literature review of research exploring accompanied paediatric interactions. Exclusion criteria included: research referring to children outside the 6–12–years age group, non-medical settings, or settings that were not considered relevant to primary care in the UK.	The child's role and involvement in accompanied paediatric interactions.	In the (21) studies identified for inclusion, children were found to contribute an average of 3% to 14% of talk in accompanied interactions. Children contributed more talk to information gathering segments of consultations and less time to treatment and planning segments of consultations. The authors observed that many studies of accompanied paediatric consultations leave out the child's role.

Used in phase of analysis:	Author(s) and Year	Description	Focus of analysis	Summary of findings / description of conceptual frameworks.
1 & 2	Fortinsky (2001)	The authors examined research issues and questions regarding the interactions of people with dementia in accompanied medical interactions.	How participant (patient and companion) characteristics may alter the quality of the interaction for patients with dementia in healthcare triads.	The authors suggest that up to 60% of dementia patients may be accompanied to primary care appointments. A number of participant characteristics and potential effects of these on the quality of the encounter for dementia patients are discussed in the paper.
1 & 2	Gabe et al (2004)	The authors present a theoretical framework for understanding 'partnership' in accompanied interactions with child patients.	Development of a framework for understanding paediatric encounters in relation to doctor-patient 'partnership'.	The authors concluded that 'partnership' is generally overlooked in accompanied medical encounters with child patients. The authors suggest focusing on three elements of accompanied interactions: the significance of the organisational and legal setting, the perspectives that the different parties bring to the clinical encounter, and the kinds of coalitions that might form in the interaction. The authors suggest that the establishment of policy frameworks and shifts in medical and social care policy and culture help determine participant behaviours and the content of medical interactions.
1 & 2	Glasser and Prohaska (1999)	Data were gathered immediately before and visits to rural general practices using survey methods. 104 patients and 28 accompanying persons completed the survey.	Rate of patient accompaniment, accompanied patient and companion characteristics and reasons for patient accompaniment in rural areas.	One third of the patients that completed the survey were accompanied to their visit. Accompanied patients were significantly more likely to be women, have lower incomes, and report poor health status than patients attending alone. There was no significant difference between accompanied and non-accompanied patients regarding the number of people available that they could talk to about their health concerns. Transportation was identified as the main reason for patient accompaniment (reported as a main reason by 66% of patients).

Used in phase of analysis:	Author(s) and Year	Description	Focus of analysis	Summary of findings / description of conceptual frameworks.
1 & 2	Glasser, Prohaska and Gravdal (2001)	Data were gathered immediately before and visits to rural general practices using survey methods. 185 patients completed the survey.	Rate of patient accompaniment, accompanied patient and companion characteristics and reasons for patient accompaniment in rural areas.	185 patients completed surveys, of these, 72 (39%) were accompanied to their visit. Accompanied patients were significantly more likely to be women, have lower incomes, and report poor health status than patients attending alone. Nearly half of companions were the patient's spouses. Transportation was identified as the main reason for patient accompaniment (reported as a main reason by 73% of patients).
1 & 2	Hasselkus (1992)	Non-participant observation was used in 40 accompanied interactions. Discourse analysis methods using a typology of 26 caregiving problem situations (divided into two broad topical themes for discussion, healthcare and life world) were used to analyse data.	Topical healthcare and life world themes were explored in relation to problem situations and exchanges of meaning, including the structure and sequence of interactions between participants.	Of the 31 companions that participated in the study, the majority (19) were the patient's adult child(ren), or the patient's spouse (10). The majority of companions (22) were female. Of the problem situations discussed, 'healthcare' was the most prevalent, followed by 'eating', 'moving around' and 'risk'. Companions were frequently observed to contribute to or assume traditional doctor responsibilities, for example, making diagnoses and interpreting patient symptoms. Doctor's sometimes viewed the companion as a patient substitute or a secondary patient. The authors observed that of all participants, patients contributed the least amount of talk (discourse space) in the encounters. The authors observed that there was no great frequency of the coalitions proposed by Coe and Prendergast (1985), and that the coalitions did not feature heavily in encounters.

Used in phase of analysis:	Author(s) and Year	Description	Focus of analysis	Summary of findings / description of conceptual frameworks.
1 & 2	Main et al (2001)	Direct observation of medical encounters and interviews with patients and companions. The effect of companions was analysed using qualitative methods - field notes were used to develop case examples. Interview data analysed using content analysis and statistical methods.	Patient accompaniment, accompanied patient and companion characteristics. Domains of outpatient visits in which family-oriented content was discussed was also analysed.	560 (35%) of the 1600 patients observed were accompanied to their visit, the majority of which were children and older (elderly) patients. Family members usually accompanied patients. Companions were much more likely to be women (73%). 923 visits (58%) were defined as family-oriented. Physician knowledge of family context is an important factor in medical decision-making and was classified as 1 of 6 types.
1 & 2	Prohaska and Glasser (1996)	Data were gathered using survey and semi-structured interview methods. Data were gathered before and one week after the visits.	Rate of patient accompaniment, accompanied patient and companion characteristics and medical care decision seeking activities of patients by accompaniment status.	50% (68) of the patients were accompanied to their visit. Females and those with less education (0-8 years) were significantly more likely to be accompanied to the visit. Patients attending alone were significantly more likely to have discussed the necessity of the visit, transportation to the visit and how to pay for the visit with someone prior to the appointment compared to patients that were accompanied.

Used in phase of analysis:	Author(s) and Year	Description	Focus of analysis	Summary of findings / description of conceptual frameworks.
1 & 2	Rosland et al (2011)	Written survey of 439 adults with diabetes or heart failure and 88 of their primary care physicians (PCPs).	Rate of patient accompaniment, accompanied patient and companion, determinants of patient experiences in accompanied interactions.	48% of the patients with diabetes or heart failure report regular accompaniment to primary care visits. Patients with four or more comorbid illnesses were more likely to report being accompanied to visits. Over three-quarters of patients reported that they were more likely to understand the doctor's advice if they were accompanied. Accompaniment was associated with greater satisfaction among patients. The majority of doctors viewed patient accompaniment positively, although one-third perceived accompanied consultations to last longer and be more burdensome.
1 & 2	Schilling et al (2002)	1294 patient visits were observed to determine the frequency of accompaniment. 121 unaccompanied patient's, 200 accompanied patients (and companions) and 57 physicians agreed to participate in the second (survey) phase of the research.	Rate of patient accompaniment, accompanied patient and companion characteristics, reasons for accompaniment.	Of the 1294 observed patient visits, companions were present for 374 (29%) of patient visits. However, only 212 of the companions (16%) went into the examination room. Patients were usually accompanied by their spouse. Older patients (>44 years of age) were significantly more likely to be accompanied than younger adult patients. Patients with cases of greater medical and social complexity (as perceived by the doctor) and those that self-reported less education (<high school) were significantly more likely to be accompanied. 50% of all patients and companions reported that the reasons of accompaniment centred on; help with transportation, to provide company, to help communicate concerns to the doctor and to help remember the doctor's instructions.

Used in phase of analysis:	Author(s) and Year	Description	Focus of analysis	Summary of findings / description of conceptual frameworks.
1 & 2	Street and Millay (2001)	Conceptual development of patient participation in medical encounters with adult patients.	How to analyse adult patient participation in medical encounters (with a focus on accompanied interactions).	The authors observed that the most popular approach to data collection in empirical studies of doctor-patient interactions was to audio or video-record encounters. The most popular method of analysing audio or video-record encounters is noted as process analysis. Verbal acts of active participation (definitions and applications) are discussed in relation to accompanied interactions, for example, asking questions, describing health experiences, expressing concerns, giving opinions, making suggestions, and stating preferences.
1 & 2	Tates and Meeuwesen (2001)	The authors examined studies of accompanied paediatric interactions. The study could take place in any medical context, but must have involved audio or video recording consultations.	Evaluated research of accompanied paediatric encounters and the role of the child in these interactions.	The authors identified that it is usually the mother that accompanies children to medical visits. Among the studies included in the review, the most popular approach to analysis was identified as process analysis. The authors observed that most of the studies identified for inclusion examined accompanied interactions by analysing dyadic exchanges. The authors observed that child patients face a 'double asymmetry' in medical interactions, the institutional authority of the doctor and the status of the parent. The authors suggest that policy shifts (for example, informed consent and partnership) and the organisational and legal frameworks that shape these encounters need to be acknowledged.

Used in phase of analysis:	Author(s) and Year	Description	Focus of analysis	Summary of findings / description of conceptual frameworks.
1 & 2	Wolff and Roter (2011)	<p>Meta-analysis of observational research and survey studies of accompanied medical visits with adult patients were identified. Inclusion criteria: studies needed to present quantitative information regarding patient accompaniment and patient or family companion attributes, visit structure, communication processes, and/or outcomes of care. Studies of paediatric patients, hospitalized or terminally ill patients, emergency room patients, end-of-life care, genetic counselling, and specialty mental health (psychiatric) visits were excluded.</p>	<p>Rate of patient accompaniment, participant characteristics, duration of visits, differences in the discourse space of participants, effect of companions, patient outcomes in accompanied and unaccompanied visits.</p>	<p>10 observational studies and seven survey studies were identified for inclusion. The authors reported a mean adult patient accompaniment rate of 46%. However, of the studies included in the meta-analysis, the majority included older adult patient (over 60-65 years of age) samples. Companions were predominantly female, and usually the patient's spouse/partner. Six studies examined differences in visit duration; pooling the results, the authors found that accompanied visits were significantly longer than unaccompanied visits. Three studies of participant verbal activity were included: differences between the discourse space of 'patient party's' (patient and companion) in accompanied interactions and patients alone in unaccompanied interactions were not found to be significant. Patients contributed significantly more talk than companions in accompanied interactions. More information giving was observed in accompanied as opposed to unaccompanied interactions. The presence of a companion was not observed to result in negative patient outcomes.</p>

Used in phase of analysis:	Author(s) and Year	Description	Focus of analysis	Summary of findings / description of conceptual frameworks
1 & 2 & 3	Aronsson and Rundstrom (1988)	The authors used the Turn Allocation System (TAS) and microanalytic methods (a mixture of socio-linguistic and content analysis methods) to analyse 32 accompanied encounters.	Quantification and analysis of structural sequences. Analysis of participant turns; categorising doctor initiations as child specific allocated turns (CATs) and adult specific allocated turns (AATs). A particular focus was placed on CATs. The discourse space of participants was examined.	The authors found that children only contributed 8% of words on average to the medical consultations, with parents occupying 34% of the discourse space. Parental control was a significant factor in the ability of children to participate in the medical encounters, with parents found to intervene (answering for the child, and providing correction, elaboration or validation of child responses) in 52% of CATs. 'Low control' parents were found to act as 'mediators and cultural brokers' between the doctor and child, 'high-control' parents controlled child-doctor interactions by appropriating CATs.
1 & 2 & 3	Bindera et al (2010)	Analysis of recorded interactions using process analysis methods. Pre and post visit questionnaires were completed by patients and companions regarding concerns not voiced when stating their reasons for the consultation. Patients also completed post-visit questionnaires regarding how they felt during the consultation.	The ability of adolescent patients to express personal concerns in accompanied and unaccompanied interactions; compared to pre and post visit questionnaire responses.	64% of the adolescent patients were accompanied to their visit; accompaniment was more marked among younger adolescents. Male and female adolescents were equally likely to be accompanied. The companion was usually the mother of the adolescent patient (80%). In accompanied interactions, the doctor rarely asked the companion to leave the room (only in 4% of visits). Adolescents attending alone were more likely to report personal concerns to the doctor compared to accompanied adolescents. Patients attending alone reported greater satisfaction. Companions over-estimated the ability of adolescents to talk freely in the accompanied interactions.

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1 & 2 & 3	Buchbinder (2009)	The author used conversation analysis to analyse the interactions of an adolescent with diabetes, the patient's mother and a nurse.	The extent patient autonomy is facilitated and constrained by the companion and nurse. The encounters were into problem identification, development of solutions and moments of transition segments.	The adolescent's autonomy was emphasized during the identifying problems phase of the consultation and restricted during the formulating solutions phase of the consultation. During the solution finding phase of the consultation the author observed increased interjection of concerns by the third party (mother) and the subsequent reconceptualization of problems. When the nurse needed other, additional or privileged information she often referred to the companion (mother). However, the companion (mother) was observed to raise important issues that may not have emerged in her absence or may have been obscured if she had remained silent.
1 & 2 & 3	Cahill and Papageorgiou (2007b)	The authors used conversation analysis to analyse child participation in 31 accompanied encounters.	Four main aspects of interaction were examined, seating positions, interruptions, inviting the patient to speak, and switching pause.	Child patients were largely marginalised from the conversations; however, children usually did participate when asked to do so. Children were observed to 'take time' answering questions, the authors suggest that doctors may direct more attention to parents as a result. The parent (companion) was less likely to answer the doctor's question if the doctor was making eye contact with (gazing) at the child. The authors observed that if parents could not voice their concerns early in the encounters, then they were more likely to interrupt child-doctor talk later in the encounters. More triadic talk was observed when participants were sat in a triangular position at equal distances from each other.

Used in phase of analysis:	Author(s) and Year	Description	Focus of analysis	Summary of findings / description of conceptual frameworks.
1 & 2 & 3	Karnieli-Miller et al (2009)	The authors map the nature, form and manner of participant involvement in 25 accompanied interactions using microanalytic methods (grounded theory and textual analysis).	Participant involvement in topical consultation areas and analysis of 'communication shifts' in the encounters were analysed.	The authors identify 'triadic' communication as consisting of a series of alternating dyadic exchanges. The authors observed that companions typically tried (with vary degrees of success) to become involved in doctor-patient dyadic exchanges throughout the consultations analysed. The doctor's often shifted from talking with and to the patient, to talking to the companion about the patient, and in some cases ignoring the patient. Companion-doctor dyadic exchanges (in which the patient was marginalised) were more frequently observed in the introduction and summation/disclosure phases of the consultations.
1 & 2 & 3	Pantell et al (1982)	The authors used process analysis methods (a modified version of the Bales Interactive Process Analysis (IPA) system) to analyse 115 encounters. Demographic and situational characteristics of patients were gathered using questionnaires.	The authors aimed to identify demographic and situational characteristics that influenced the extent of communication between the doctor and child.	The authors found a considerable amount of communication between the doctor and child in the interactions (accounting for 45.5% of the child's communication during visits). However, companions (parents) received considerably (4.4 times) more information than child patients during the visits. Doctors interacted differently with parents and children. Doctors obtained more information about the problem from children, but provided more feedback to parents. Patient characteristics (race, socioeconomic status, type of problem, and previous encounter with the doctor) did not alter doctor's communication patterns in the encounters. However, the authors observed that boys were given significantly more information than girls in the interactions.

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1 & 2 & 3	Sakai et al (2011)	Content analysis methods were used to quantify participant discourse spaces and code linguistic expressions of power, using measures of verbal dominance and pronoun indicators in 86 accompanied interactions. Patients and companions answered a range of questionnaires 2–3 days after their visit.	Participant discourse spaces and linguistic expressions of power (using measures of verbal dominance and pronoun indicators) were assessed against patient and companion satisfaction scores.	Companions were mostly female (60%) and the patient's spouse (50%) or adult child (24%). Doctors were the most verbally active participants in the encounters, occupying an average of 83% of the discourse space. On average, patients were observed to speak marginally more than companions (10% versus 6% of the discourse space). Companions were observed to speak more (occupy more discourse space) if the patient had (/was subsequently diagnosed with) dementia. No correlation was observed between the discourse space of doctors and patient/companion satisfaction scores.
1 & 2 & 3	Schmidt et al (2009)	Process analysis methods were used to analyse 23 accompanied interactions. The verbal contributions of participants were quantified. Patient's cognitive status was assessed using the Mini-Mental State Examination (MMSE) post visit. Companions completed 'patient' satisfaction questionnaires (Primary Care Assessment Survey) post visit.	The authors quantified participant discourse spaces and analysed (Alzheimer) patient participation (discourse space) against their (patients) cognitive status (measured by the Mini-Mental State Examination (MMSE) score). Companion (caregiver) satisfaction was also assessed.	Companions were predominantly female (78%) and the patient's spouse (65%) or adult child (35%). In the encounters, doctor's verbal participation (53%) was greater than that of caregivers (31%) and patients (16%). Caregivers (companions) contributed nearly twice as much verbally than patients. The discourse space of doctors was not related to patient's cognitive status. However, patients contributed less and their companions contributed more if the patient had a low cognitive status (as measured by the MMSE). Companions (caregivers) satisfaction with the visit was positively correlated with their own verbal participation.

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1 & 2 & 3	Stivers (2001)	The author used conversation analysis to analyse 100 accompanied encounters randomly selected from a corpus of 291 paediatric encounters	The focus of the analysis was 'establishing the reason for the visit'.	Companions were usually the child's mother. The doctor did not initiate a problem presentation from the child or accompanying person (parent) in 30% of the consultations analysed. It was observed that this was either because the child had already presented the problem or because the doctor posed a history-taking question (often to the parent); however, these phases (history-taking questions) were excluded from the analysis.
1 & 2 & 3	Tates and Meeuwesen (2000)	105 accompanied encounters (recoded over nearly 20 years) were selected from a large collection held by the Netherlands Institute of Health Services Research and analysed using mixed methods (qualitative and content analysis methods). The authors used an expanded version of Aronsson and Rundstrom's (1988) Turn Allocation System (TAS) to analyse the encounters.	Quantification and analysis of structural sequences. The authors examined the asymmetry and strategic control of doctor–parent–child communication. Focus was placed on how child age effected turn taking and the interactive control and dominance of adults.	GP's contributed 51% of the talk in the encounters. The child's contribution to the encounters was limited at 9.4%. The communication between doctor-patient (child) was 18.2%. GP's allocated most turns to the parent (36%), only 13% of GP turns were allocated to the child. GP's allocated more child turns during the medical history-taking segment of the consultations. During the discussion and advice and conclusion segments, GP turns were mainly allocated to parents. Older children were allocated more GP turns than younger children. However, parental control in the interactions was not associated with child age. Children participated more actively in these encounters over time (e.g. more child participation was observed in the consultations recorded in the early 1990's compared to those recorded in the late 1970's).

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1 & 2 & 3	Tates et al (2002a)	105 accompanied encounters (recoded over nearly 20 years) were selected from a large collection held by the Netherlands Institute of Health Services Research and analysed using mixed methods (qualitative and content analysis methods).	Differences between how doctors and parents (companions) of child patients enabled or constrained the child's participation in the encounters were analysed. A typology of 'adult' behaviours that support versus non-support child participation were identified and developed.	The doctor's were frequently observed to try and engage child patients during the opening stages of the encounters. However, despite these initial efforts, 90% of the consultations were classified as not resulting in child participation. The authors observed that during the final segment of the consultations (where diagnosis and treatment options were discussed) the child was particularly marginalised and typically excluded from the discussion. However, the authors suggest that the low degree of child participation observed is not simply a consequence of adult behaviour. Children were rarely observed to turn to their parent for support, or to intervene in 'adult' discussions. Therefore, the authors suggest that the low degree of child participation observed in paediatric (accompanied) encounters is co-constructed by all three participants in these interactions.

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1 & 2 & 3	Tates et al (2002b)	106 accompanied encounters (recoded over nearly 20 years) were selected from a large collection held by the Netherlands Institute of Health Services Research and analysed using mixed methods (qualitative and content analysis methods).	Differences between how doctors and parents (companions) of child patients enabled or constrained child participation in the encounters were analysed.	Child patients were observed as marginalised from much of the discussion in the encounters. Parents were frequently observed to assume parental responsibility and speak on behalf of their child; this was rarely questioned or addressed by doctors - who reinforced this behaviour by routinely engaging with and addressing parents. However, the authors observed that the older the child was, the more doctors addressed the child directly. Doctors in consultations recorded in the late 1970s were more likely to address the parent and constrain the child's participation than those in consultations recorded in the early 1990s.
1 & 2 & 3	van Staa (2011)	Alongside conducting (31) face-to-face interviews, Q-methodology, 3 focus groups (27 healthcare providers) and web-based questionnaires (960 adolescents), the author analysed 39 outpatient visits with accompanied and unaccompanied adolescent patients with chronic conditions.	Adolescent preferences for communication during medical encounters were examined. The author employed Goffman's (1959) dramaturgical metaphor to analyse participant roles, behaviours and participation in 39 medical encounters.	70% of the (39) adolescent patients (12 to 19 years of age) were accompanied to their visit. All adolescents reported wanting to be involved as partners in healthcare encounters. The author observed that adolescents were often 'bystanders' in the consultations and their participation was frequently neither requested nor encouraged. It was observed that the adolescent's companion (parent) often filled the void between doctor and patient interaction.

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1 & 2 & 3	Wassmer et al (2004)	The authors used a modified version of the Roter Interaction Analysis System (RIAS) to assess 51 accompanied interactions. Questionnaires were used to assess parent and child perceptions of the doctor's communication skills.	The discourse spaces of participants was analysed and classified in accordance to different behaviours/ communication (e.g. affective behaviour, directive talk, affective talk, social conversation (small talk), instrumental talk).	Children were observed to contribute very little to the conversations (4%); doctors were observed to contribute the most talk (61%). Doctor communication was mainly instrumental (84%) (e.g. asking questions, giving information or instructions). Parent communication was predominantly classified as information giving (83%). Children contributed the most social conversation (19%) in the encounters. There were no significant correlations between patient or companion satisfaction and the doctor's communication behaviours.
1 & 2 & 3	Zaleta et al (2010)	A modified version of the Roter Interaction Analysis System (RIAS) (process analysis) was used to analyse 54 accompanied interactions in a dementia clinic. Patient-centred communication was examined.	The frequency of patient-centred doctor behaviours and the extent that doctors expressed positive affect were assessed.	Companions were mainly the patient's spouse (63%) or adult child (22%). Of the patient-centred doctor behaviours identified, doctors most frequently displayed positive rapport building behaviours, followed by facilitation and patient activation behaviours. Doctors who demonstrated more patient-centred communication also displayed greater positive affect in the encounters.

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1 & 2 & 3 & 4	Beiseker (1989)	Recorded interactions were analysed using process analysis - a modified version of the Bales Interactive Process Analysis (IPA) system.	Rate of patient accompaniment, duration of visits, companion participation, and the role of companions were assessed.	12 of the 21 older patients were accompanied by a companion to their visit. Older (elderly) patients were more likely to be accompanied to the visit than their younger counterparts. No significant difference in the length of unaccompanied and accompanied consultations was observed. The author therefore suggested that companions take time away from patients in accompanied interactions. Doctors were observed to direct fewer comments to companions than the companions directed to doctors and the author deduced that companions responded or initiated comments when doctors were not addressing them. Companions were observed to play three roles: watchdog, significant other, and surrogate patient.
1 & 2 & 3 & 4	Clayman et al (2005)	Data were gathered from 93 patients and their companions and analysed using a modified version of the Roter Interactive Analysis System (RIAS) (process analysis).	Patient and accompanying person decision-making behaviours were analysed based on an expanded framework of autonomy enhancing behaviours and detracting behaviours. The authors analysed eight elements of informed medical decision making.	Patient companions were mainly spouses (46%) or adult children of patients (36%). 21% of companions in the data prompted patients to discuss topics, and one third of companions introduced medical topics not previously discussed by the patient or doctor. The authors observed that the majority of companion contributions enhanced patient autonomy and that companions helped to facilitate doctor-patient discussions. 52% of companions in the data engaged in at least one autonomy enhancing behaviour and did not display any autonomy detracting behaviours and 41% of companions engaged in at least one behaviour of every kind (autonomy enhancing and detracting). However, no companions engaged in only autonomy detracting behaviours.

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1 & 2 & 3 & 4	Coe and Prendergast (1985)	Seven accompanied interactions were analysed using micro-analytic methods to examine the formation of coalitions and companion roles.	The authors analysed the form, content and sequence of participant utterances - focusing on the formation of goal-orientated coalitions using microanalytic methods. The authors also identified different roles companions occupied in the encounters.	The authors observed that several (multiple) coalitions might form within the bounds of a single (triadic) consultation. Coalitions varied in duration (ranging from 10 to 65 lines of transcript), topic, objectives of members, and alignment of members. Common coalition objectives were found to include information seeking, obtaining permission, obtaining compliance and ending the encounter. The strongest coalition identified in the interactions was the patient-doctor alliance. The authors reported that 'patient party' (patient and companion) coalitions tended to occur when doctors were preoccupied and did not centre their attention on the patient party. The authors observed that attempts to form coalitions did not always succeed in the data. The authors observed that some companions made efforts to form coalitions with the doctor to achieve their aims and objectives. However, that these efforts were most often deflected by the doctor, who redirected the question (to the patient) or changed topic. The authors concluded that more coalitions occur in interactions when information is not easily obtainable from the patient and the doctor is dependent on caregivers for information. Companions were observed to occupy 'medication manager', 'interpreter', 'negotiator', or 'caretaker' roles.

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1 & 2 & 3 & 4	Cordella (2011)	Nine triadic medical encounters in an outpatient cancer clinic in Chile in which patients were accompanied were analysed. Accompanying person roles were coded using qualitative and content analysis methods.	The types of roles companions (accompanying persons) played during the encounters were analysed.	Seven accompanying person roles were identified: secretary, carer, financial assistant, health advisor, social communicator, reporter and partner. Of the seven accompanying person roles, 'carer' was used most frequently observed and 'carer' and 'health advisor' roles were displayed across all interactions. The author observed that when the 'partnership' role emerged it played an important part in the consultation. The author observed that the accompanying person could relieve the patient of many daunting tasks, support the patient, and provide, additional, valuable information that may not have emerged in their absence.
1 & 2 & 3 & 4	Eggy et al (2006)	28 oncology interactions were analysed using content analysis methods. Discussions of 'bad news' were examined.	The frequency and topical content of information seeking in 'bad news' discussions.	24 of the 28 (86%) of the oncology patients were accompanied to their visit. Treatment, diagnostic testing, diagnosis, and prognosis were the most frequently occurring information seeking topics for both patients and companions. Of these topics, companions were found to be particularly active in diagnostic testing discussions.
1 & 2 & 3 & 4	Eggy et al (2011)	Content analysis was used to assess variations in question asking behaviours in oncology interactions. The authors coded interactions using the using the Karmanos Information Seeking Analysis System (K-ISAS).	Variations in participants question asking behaviours in accompanied and unaccompanied interactions were assessed.	Of the 109 patients participating in the study, 73% (n = 80) were accompanied during the visit by at least one companion (the majority by their spouse). The authors found that significantly more question asking took place in the accompanied interactions. Companions were observed to ask significantly more questions than patients in the accompanied interactions.

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1 & 2 & 3 & 4	Ellingson (2002)	Nine accompanied interactions were analysed. Participant observation of the clinical environment was undertaken (with field notes taken). Recordings were analysed using qualitative methods (grounded theory).	Estimates of patient and companion verbal participation were discussed in relation to companion roles and topical areas of discussion.	Eight companion roles were identified: 'memory aid', 'emotional support', 'transcriber', 'aid in decision making', 'companion', 'elaborator', 'advocate', and 'interpreter'. Companions were observed to play multiple roles during the course of a single consultation. Companions performed more active roles in encounters when mental health and medication topics were raised. Companions who were highly verbally active tended to aid in patient decision-making, serve as a memory aid, and elaborate on patient responses.
1 & 2 & 3 & 4	Gilliam et al (2009)	Observational study of recorded encounters between neurology (epilepsy) patients (n=60) (and where applicable their companions) and neurologists in the community using microanalytic (discourse and socio-linguistic) methods.	Analysis of (negative) side effect discussions.	Companions were present in 32% (19/60) of the visits. Companions were predominantly family members, and most often the patient's spouse or partner. Neurologists initiated the majority of all side effect assessments. The presence of a companion resulted in lengthier, more detailed discussion of side effects. Companions helped to facilitate doctor-patient discussions by providing additional information about side effects from a neutral perspective, and helped to track changes in patient symptoms over time.

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1 & 2 & 3 & 4	Greene et al (1994)	A matched sample of 15 accompanied patients and 15 unaccompanied patients were recorded. The authors used the Multidimensional Interaction Analysis (MDIA) system to analyse data, the MDIA combines microanalytic and process analysis methods.	Using the MDIA, the quality of questioning, informing, and supportiveness on specific topic areas by all participants were examined. Analysis of the frequency of other interactional participant behaviours, e.g. interruptions, use of social amenities, compliments, and negative remarks was also undertaken. The frequency of topics raised by participants were coded and calculated.	No significant difference in the duration of accompanied and unaccompanied encounters was observed. The authors observed that the companion answered for the patient at least once in 73% (11) of the accompanied visits observed, even though the patient was capable of doing this himself or herself. The authors found that doctors and companions often talked about the patient (older person) rather than with them (using pronouns such as 'she' or 'he'); physicians were observed to do this an average of 12 times per visit and accompanying persons an average of 18 times per visit. Patients were observed to be significantly less assertive and expressive in the accompanied interactions. However, the presence of a companion was not associated with differences in doctor responsiveness (the quality of question asking, information giving and supportiveness). The authors reported no significant difference between the content of topics raised by doctors in accompanied and unaccompanied interactions.

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1 & 2 & 3 & 4	Ishikawa et al (2005a)	Data were analysed using process analysis - a modified version of the Roter Interactive Analysis System (RIAS). 82 unaccompanied patients and 63 patients and their companions participated. Two different types of triadic consultations were included, a 'typical' triad of patient, doctor and companion (who was not a patient) (n=37) and a 'double-patient' triad consisting of a doctor and two patients (who were both 'seen' in the consultation) (n=26). These triadic groups were merged in some analyses (e.g. for discourse space analyses). Pre and post visit questionnaires were administered to examine participant role intentions.	Participant discourse spaces and topical analysis of patient and companion talk in accompanied and unaccompanied interactions were examined. Patient expectations of the role of the companion in the encounters, and the companion's intention of their own role were analysed. The role of companions as 'advocates', 'passive participants', or 'antagonists' were explored.	Accompanied interactions were significantly longer than the unaccompanied interactions. Elderly adults and those with less education were significantly more likely to be accompanied to the visit compared to younger older adults. The discourse space of 'patient parties' (patients and companions combined) in accompanied interactions was not significantly different to the discourse space of patients in unaccompanied interactions. Patients in accompanied interactions contributed significantly less than patients in unaccompanied interactions. The most frequent companion role observed in the data was that of patient 'advocate'. Companion intentions to assume a direct (communication) role were significantly higher than patient expatiations. When the patient was older and in poorer health, the companion's indirect and direct role intentions were observed to be significantly higher. Expectations of the companion's role were significantly higher among male and poorer health status patients. When patient expectations of the companion (direct/ indirect role) were higher, or when companion's expectations of their (direct/indirect) role were higher, the companion was more verbally active, gave more (biomedical/psychosocial) information and asked more questions. When patients had higher expectations of an indirect role, companions were more supportive of patient talk. Companions were observed to express significantly less emotion than patients in accompanied interactions. Unaccompanied patients contributed significantly more positive talk to the interactions than patients in accompanied interactions. Proportionally more companion talk was supportive as opposed to detractive in the accompanied interactions.

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1 & 2 & 3 & 4	Ishikawa et al (2005b)	Data were analysed using process analysis, specifically a modified version of the Roter Interactive Analysis System (RIAS). 82 unaccompanied patients and 63 patients and their companions participated. Two different types of triadic consultations were included; please see Ishikawa et al (2005a). Pre and post visit questionnaires were administered to examine patient centred communication.	Participant discourse spaces and topical analysis of patient and companion talk in accompanied and unaccompanied interactions were analysed against patient centred communication.	The summary of results findings detailed in Ishikawa et al (2005a) is relevant here. Accompanied patients were more likely to rate the visit as less patient centred, especially if the appointment lasted less than 10 minutes (however these results were not significant). Verbally active patients (in accompanied and unaccompanied interactions) rated their visits as more patient-centred.
1 & 2 & 3 & 4	Labrecque et al (1991)	Process analysis methods (a modified version of the Physician Behaviour Check List (PBCL)) were used to code doctor behaviours in accompanied (99) and unaccompanied (374) oncology visits. Time spent during visit, reason for the visit, and performance status (using the Eastern Cooperative Oncology Group scale, ECOG) were recorded. Variables were measured against the results of Patient Satisfaction Questionnaires.	Doctor behaviours in accompanied and unaccompanied cancer patient visits and patient satisfaction were analysed.	Age was not a determining factor of patient accompaniment in the oncology setting; younger cancer patients (18-59 years of age) were as likely to be accompanied to visits as older cancer patients (over 60 years of age). Of the cancer patients accompanied to visits (n=99), 64% were accompanied by a spouse, 10% by their adult child, 6% by another relative and 19% by unknown companions. Doctor behaviour was affected by the presence of a companion and the patient's health performance status. Doctors were significantly less likely to provide emotional support to accompanied patients and to (non-symptomatic) patients attending alone. Patient accompaniment was not correlated with patient satisfaction; patients with poorer health status (those with poorer functioning) reported being less satisfied.

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1 & 2 & 3 & 4	Oguchi et al (2010)	Authors coded data using the Verona Coding Definitions of Emotional Sequences for Cues and Concerns (Verona-CoDES-CC and VERONA-CoDES-P) (content analysis) and explored patient emotional cues/concerns and practitioner responses in accompanied (34) and unaccompanied (17) oncology consultations.	Analysis of patient emotional cues/concerns and practitioner responses.	Two-thirds (34) of the cancer patients were accompanied to their appointment, one-third of patients (17) attended alone. Patients displayed more emotional cues/concerns than companions (an average of 3.3 patient cues per consultation were observed and 81% of emotional cues were attributed to patients in accompanied interactions). However, accompaniment was observed to hinder (decrease) nurse response to patient's emotional cues and concerns.
1 & 2 & 3 & 4	Shields et al (2005)	30 participants were randomly assigned to be accompanied (13) or unaccompanied (17) to visits. The authors coded the encounters using the Measure of Patient-Centred Communication (MPCC) and Rochester Participatory Decision-Making (RPAD) scales. The total word counts of participants were calculated and analysed. A patient satisfaction survey was issued after the encounters.	Differences between the duration and discourse spaces of participants and patient-centeredness and satisfaction in accompanied and unaccompanied encounters were analysed.	Using total word count as a proxy measure, no significant difference was observed between the duration of accompanied and unaccompanied encounters. No significant difference in the discourse spaces of patients in unaccompanied interactions and patients and companions combined 'patient parties' in accompanied interactions was observed. Patients occupied significantly more discourse than companions in accompanied interactions. The authors observed that doctor's made statistically longer turns in encounters where a companion was present. No significant difference between accompaniment status and patient-centeredness and satisfaction was observed.

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1 & 2 & 3 & 4	Street and Gordon (2008)	The authors compared the communication of unaccompanied patients (48), accompanied patients (84) and companions during initial lung cancer consultations. The authors used process analysis methods to code and categorise participant utterances against communication categories (active participation and use of facilitative communication). Patient satisfaction scores were compared to companion participation and roles ('advocate', 'partner' or 'observer').	Participant discourse spaces, companion participation and patient satisfaction.	No significant differences in 'patient party' (patient and companion) discourse space was observed between accompanied and unaccompanied interactions. Over half of the companions were classified as 'passive' (contributed <40%). One third of companions were classified as 'active' (contributed >60%). Companions contributed proportionally less talk than patients in accompanied interactions. However, the authors observed that when companions did speak it was usually to actively participate (ask questions, express concerns, state an opinion or preference). Companions were more active when proportionally more of doctor talk was facilitative (partnership-building, supportive talk). When companions were 'passive', patients displayed more assertive behaviours. Patient satisfaction was generally high and not correlated with the degree of companion 'active' participation. Patient satisfaction was significantly lower when the companion and patient had similar levels of participation.

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1 & 2 & 3 & 4	Tsai (2000)	Socio-linguistic (CA derived) methods were used to code 15 recorded interactions with older patients, their companions and a doctor.	Differences between patient and companion participation in information-providing cycles and non-information-providing cycles in accompanied encounters were examined. Analysis of the topical content of information and the extent that patient and accompanying person information was elicited or volunteered was examined.	The author found that patients contributed significantly more (approximately twice as much) than companions to information-providing cycles. The author classified the content of 'information-providing cycles' into five categories; of these, biomedical information (42%) and management information (37%) were the categories most frequently observed, followed by daily routines and personality information (11%), pedigree information (10%), and physical exam information (0.5%). Patients were found to be the primary providers of information across all five categories. However, only patient provision of biomedical information and daily routine and personality information were significantly greater than companion provision. The author identified eight discourse patterns of question-response sequences, where the 'patient party' (patient and/or companion) provided information to the doctor. Patients in the data were significantly more likely to respond to the doctor's questions alone and provide a sole answer (45%) compared to companions (15%). Patients were significantly more likely than companions to volunteer 'information-providing cycles'. However, companions regularly volunteered information or responded to the doctor's questions when they had not been invited (by the doctor) to do so.

Used in phase of analysis:	Author(s) and Year	Description	Focus of analysis	Summary of findings / description of conceptual frameworks.
1 & 2 & 3 & 4	Wolff and Roter (2012)	The authors used a modified version of the Roter Interaction Analysis System (RIAS) to analyse interactions of older patients in accompanied (80) and unaccompanied (310) interactions. Patients completed surveys (that included measures of health function) pre and post visit.	Differences between the duration, patient and companion characteristics, participant discourse spaces (patients and companions combined vs. doctors), and doctor's use of patient centred communication in accompanied and unaccompanied encounters were examined.	Accompanied patients were significantly older, more likely to live with others, to have less than high school education and have poorer physical health than unaccompanied patients. No significant difference in the duration of accompanied and unaccompanied encounters was observed. No significant difference in the discourse space of patients in unaccompanied and patients and companions combined ('patient parties') in accompanied interactions was observed. Companions occupied significantly less discourse space than patients in accompanied encounters. Patients in unaccompanied interactions contributed significantly more positive talk than patients in accompanied interactions did. Doctors were observed to engage in significantly less question asking and partnership-building in accompanied interactions. No significant differences between accompaniment status and patient-centred communication outcomes were observed.

Glossary

EPS	Epilepsy
PNES	Psychogenic non-epileptic seizures
Dissociative	Disruptions or breakdowns of memory, thinking, awareness, identity, consciousness or perception
Ictal	A physiologic state - an acute epileptic seizure
Paroxysmal neurological symptom	Temporary neurological disturbance (such as loss of consciousness)
Postictal	Occurring after a physiologic state - an acute epileptic seizure
Postsyncopal	Occurring after a loss of consciousness resulting from insufficient blood flow to the brain (faint)
Preictal	Occurring before a physiologic state - an acute epileptic seizure
Presyncopal	Occurring before a loss of consciousness resulting from insufficient blood flow to the brain (faint)
Syncope/syncopal	Loss of consciousness resulting from insufficient blood flow to the brain (faint)
TLOC	Transient loss of consciousness
AED	Anti-epileptic drug
CT	Computed Tomography
EEG	Electroencephalogram
ECG	Electrocardiography
MRI	Magnetic Resonance Imaging
Video-EEG	Video-electroencephalogram
CI	Confidence interval (95%)
OR	Odds Ratio
SD	Standard Deviation
C:	The companion is speaking
D:	The doctor is speaking
P:	The patient is speaking

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