

THE UNIVERSITY OF HULL

An exploration of illness representations in older age

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by

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Acknowledgements

I would like to dedicate this thesis to all the participants who so openly shared their inspiring experiences with me and to all older people out there who live with epilepsy.

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Overview

The portfolio thesis is divided into three parts:

Part one is a systematic literature review exploring the literature in relation to illness representations and older people living with health conditions. A systematic search of three databases identified ten studies in the area. The findings of the studies are analysed using a qualitative method to identify what has been examined in the literature to date. Three themes were extracted from this method: ‘associations between the constructs of the common sense model of illness representations’, ‘coping and health outcomes’ and ‘variables associated with illness representations’. The findings are discussed in relation to research in chronic illness management, clinical implications and directions for future research.

Part two is an empirical paper that explores the experience of epilepsy in older age. The study employs an interpretative phenomenological analysis. The illness representation model is used as a framework (Leventhal, Nerenz, & Steele, 1984) for conducting semi-structured interviews. Ten older people with a diagnosis of epilepsy took part in the study. Three super-ordinate and eight subordinate themes emerged from the data. These themes are discussed in relation to clinical implications and the wider literature of epilepsy, health and ageing.

Part three consists of the appendices supporting the systematic literature review and the empirical paper. It also includes a reflective statement of the research process.

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Part One

Systematic Literature Review

A systematic review of illness representations in older people

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Abstract

The Common Sense Model of illness representations (CSMIR) (Leventhal et al., 1994) has been extensively investigated in relation to chronic health conditions in the general population. However the literature on the role of illness representations in older age has not been investigated to the same extent despite the high prevalence of health conditions in older people. The present study aimed to examine what has been studied to date in relation to illness representations and older people living with health conditions in this population. A systematic review of three databases (PsycINFO, MEDLINE and CINAHL plus with Full Text) was conducted in February 2013. Inclusion and exclusion criteria were applied and ten studies were identified. The findings of the studies were analysed using qualitative methods. Three main themes were identified in the literature: ‘associations between the constructs of the CSMIR’, ‘coping and health outcomes’ and ‘variables associated with illness representations’. The findings revealed a number of areas that may be of clinical importance and provide some support for the clinical relevance of Leventhal’s model of illness representations in relation to this population, defined by the relationship of the model with clinical outcomes. However the literature is limited and further research is required to examine the role of the model in clinical settings and multidisciplinary health interventions.

Key Words: illness representations, Common Sense Model, older people, health conditions, systematic literature review

Introduction

The vast majority of older people are living with health conditions (Marengoni et al., 2011). It is estimated that between 55 to 98% of people above the age of 60 have at least two co-existing health conditions and this figure continues to rise with the growing ageing population (Marengoni et al., 2011). Facing multi-morbidity in older age impairs physical functioning and psychosocial wellbeing (Byles, et al., 2005; Wong et al., 2008; Marengoni, et al., 2009).

An important aim of research in health psychology is to facilitate understanding and successful management of such conditions in order to ensure positive health and psychosocial outcomes. The Common Sense Model of Illness Representations (CSMIR) provides a useful framework to explain how people make sense of their health conditions (Leventhal et al., 1984; Leventhal et al., 1997). This model suggests that individuals form cognitive and emotional illness representations or schemata in an attempt to make sense of and manage their condition (Leventhal et al., 1984; 1997). Illness representations are personal illness beliefs informed by different sources of information including pre-existing lay and cultural explanations, information from healthcare professionals and significant others and the personal experiences of the symptoms of the condition (Leventhal et al., 1984; 1997).

The CSMIR consists of five broad domains of illness representations namely; illness label or identity, cause, timeline, consequences and cure or controllability (Leventhal et al., 1984). *Illness identity or illness label* refers to the individual's beliefs about the symptoms of their health condition. *Cause* refers to idiosyncratic beliefs about the causes of a health condition and can include biological (Heijmans, 1998), emotional

(Moss-Morris et al., 1996), psychological (Moss-Morris et al., 2002) and environmental causes (Heijmans, 1998; Heijmans and De Ridder, 1998). *Timeline* refers to beliefs associated with the duration and course of a condition, while *consequences* refer to the person's beliefs about the impact the condition has on their life. Finally, *controllability* or *cure* refers to the person's beliefs about the effectiveness of personal control and treatment regimes in managing the condition (Lau and Hartman, 1983). Two additional domains namely *emotional representations* and *illness coherence* were later on proposed by Moss-Morris et al. (2002). *Emotional representations* refer to the person's emotional reactions and feelings towards their condition. *Illness coherence* refers to the person's overall understanding of their condition (Moss-Morris et al., 2002).

The importance of illness representations in health outcomes and coping is well established in the general population. For instance, a meta-analytic review of the CSMIR across 23 different health conditions has provided support for the validity of the model and found strong relationships between illness representations, coping and health outcomes (Hagger and Orbell, 2003). Specifically, a strong illness identity defined as more perceived symptoms, a chronic timeline and serious perceived consequences were associated with poorer health outcomes and with emotional and avoidant coping strategies. Such passive coping strategies are not as effective as active coping strategies in the management of chronic health conditions (Heijmans, 1998). Furthermore, more positive representations like higher perceived controllability were associated with more adaptive coping strategies such as cognitive reappraisal and problem-focused coping as well as positive health outcomes (Hagger and Orbell, 2003).

Studies investigating illness representations often do not examine older people as a distinct group from younger populations. However, investigating the role of illness

representations separately for older people is of particular importance for a number of reasons. Firstly, the high prevalence of health conditions in this population (Marengoni et al., 2011) highlights the need to identify the ways in which older people make sense of and cope with health challenges. Secondly, the way older people make sense of health conditions may have distinct features and may be different to younger populations. For instance, older people are more likely to perceive themselves as more vulnerable to ill health and perceive illness as more serious in comparison to younger people (Prohaska, Leventhal, Leventhal, and Keller, 1985). Interestingly, despite these beliefs, the literature suggests that older people are less likely to interpret chronic physical symptoms as signs of disease or illness (Prohaska et al., 1985) and instead perceive it as part of ageing (Belgrave, 1990; Goodwin et al., 1999). Sarkisian et al. (2002) found that more than 50% of older people interpret physical, psychological and cognitive changes as part of normal ageing.

Illness cognitions and beliefs can have significant implications in the management and health outcomes of chronic health conditions. For instance, older people who perceive physical symptoms as an aspect of ageing instead of a sign of illness (Belgrave, 1990; Goodwin et al., 1999; Sarkisian et al., 2002) may not seek medical advice and appropriate treatment. There is evidence to suggest that a large proportion of older people do not seek healthcare for their unmet physical and psychological needs (Walters et al., 2001). Illness representations may have a role to play in these patterns, thus the consideration of the CSMIR in this population may be of particular importance. Additionally, the health practices of older individuals are different compared to younger people (Prohaska et al., 1985). In a study by Prohaska et al., (1985), older people used more health promoting actions and were more likely to avoid stress and control negative

emotions than younger people. Such differences may also be explained by illness representations.

Despite the importance of illness representations in the management and outcomes of health conditions and the high prevalence of ill health in older people the research on the role of the CSMIR in this population has received little attention. To the authors' knowledge no review has examined the literature in relation to older people and illness representations. Conducting a review in this area can identify how older people make sense and in turn manage health threats and can inform multidisciplinary health interventions and future research to improve illness management in this population.

The aims of the current systematic review were therefore to synthesise all the diverse strands of research investigating the CSMIR from across different health conditions in later life in order to explore what is known to date and identify areas future research could explore further. The review also aimed to evaluate the quality of the existing literature within this area.

The research questions of the review were:

- What has been examined in the literature to date in relation to illness representations in older people with health conditions?
- What is the support for the clinical relevance of the CSMIR defined by the relationship of the model with coping, health and psychosocial outcomes in this population?
- What other variables are associated with illness representations in this population?

Method

Literature Search Strategy

A systematic review of published literature was conducted in December 2012 and updated in February 2013. Three electronic databases PsycINFO, MEDLINE and CINAHL plus with Full Text were searched for relevant literature. The terms ('illness representation*') or ('common sense model') or (illness cognition*) or ('self-regul* model') or ('personal model*') were employed to capture different terms used to refer to illness representations, *and* (old* people) or (old* adult*) or (old* age) or (elderl*) or (aged), aimed to capture literature referring to older adults. The search terms for illness representations were selected after the authors reviewed key literature, theories and authors in the area (Leventhal et al., 1984; Moss-Morris et al., 2002; Hampson et al., 1990). No date limiters were applied as the purpose of the review was to explore the findings in the area to date.

The results of this literature search were limited using parameters in an attempt to identify the relevant papers (*see Figure 1*). In order to ensure relevance and quality inclusion and exclusion criteria were applied. An additional hand search of the bibliography of included articles was carried out to identify any relevant research which was not captured by the initial search strategy. One additional study was identified using this method which was later rejected as it did not meet all the inclusion criteria.

Inclusion Criteria and Quality Control

The initial search strategy produced a total of 676 results. These were reduced to 402 after age parameters were applied. The titles and abstracts of the remaining 402 articles were screened and the following inclusion and exclusion criteria were applied:

Inclusion Criteria

- i. Peer-review journal article, to ensure quality of included studies.
- ii. Written in English Language, as translation was not available.
- iii. Investigates at least two components of Leventhal's illness representation model (Leventhal et al. 1984). This inclusion criterion was applied since the purpose of the review was to investigate the CSMIR as a holistic model rather than investigate the individual constructs of the model alone.
- iv. Participants should be above the age of 60. The definition of older age is inconsistent in the health psychology literature. Some studies employ an age-cut off of 65 for defining older people (Schüz, Wurm, Warner, and Ziegelmann, 2012) while other studies employ a cut-off of 60 (Hampson, Glasgow and Zeiss, 1994). An age cut-off of 60 years old was therefore employed to maximise the inclusion of studies in the area. Studies that had looked at a mix of age groups were included if the data from the older adult group could be extracted and analysed separately.
- v. It is a primary study.
- vi. Participants have one or more health condition(s). The purpose of this review was to investigate the usefulness of the CSMIR for older people in making sense of their health condition(s). Therefore papers examining illness cognition in 'healthy' older people were not included. For the purpose of this review a health condition was defined as any condition that causes physiological changes and poses a threat to the individual's physiological and/or psychosocial wellbeing. It was also expected that the health condition will require a level of physiological and/ or psychological coping by the individual to manage such threats.

Exclusion Criteria:

- i. The study is a case study or a dissertation.
- ii. Participants are below the age of 60.
- iii. The study does not investigate illness representations.
- iv. The study is using secondary analysis.

Screening the titles and abstracts identified 50 studies whose full text and references were reviewed for the inclusion and exclusion criteria. A total of 10 articles met all the criteria. Studies were excluded from the review if the age of the participants was not specified (N =2) or was below the age of 60 (N =25), if the study did not investigate illness representations (N =8) or it did not investigate at least two components of the model (N =1), if participants did not have diagnosed health condition(s) (N =4), if it was not a primary study (N =1) and if it was a literature review (N =1).

Quality Assessment

An adapted quality assessment tool was employed to evaluate the quality of the studies included in the review (Appendix B). The authors were unable to locate a single published quality measure that would allow the quality evaluation and comparison of the diversity of the methods and designs of the studies included within this review. Therefore, three published quality measures were synthesised and adapted in order to reflect the diverse methodology employed in the area. The first measure was a Mixed Methods Appraisal tool, version 2011 (Puye et al., 2011). The second quality measure by Vandembroucke et al. (2007) was developed for the assessment of observational studies in primary health care, for example cross-sectional studies. Finally the quality measure by Harden et al. (2004) allows the assessment of studies employing qualitative

and quantitative designs that investigate people's perspectives, views and experiences. It was felt that the adapted version of these three measures captured the characteristics of all the studies included in the current review.

Sections 1, 2, 3 and 5 of the adapted scale were applicable to all the studies whereas section 4 was adapted according to the design and methodology of each study. The scores were calculated in percentages with the highest possible score being 100% and the lowest possible score being 0%. Six studies, two with the higher quality score, two with middle quality scores and two with the lowest quality scores were chosen and blindly rated for quality by the second author. Inter-rater reliability assessment was carried out and Cohen's Kappa was found to be .58 ($p < .001$). According to Landis and Koch (1977) this is considered to be a 'moderate agreement'. Discrepancies between the two authors' ratings were discussed until a consensus was reached.

Data Analysis

Qualitative narrative synthesis was chosen to analyse the results of the studies and identify common themes and constructs across the literature. This method was chosen because it allows the synthesis of findings from studies investigating different constructs and variables and using different measures and methodologies. It also allows the integration of quantitative and qualitative evidence (Dixon-Woods et al., 2005). Harden et al. (2004) highlight the importance of integrating multiple sources of evidence for policies and important issues in healthcare. Integrating multiple sources of evidence allows the review of important information in the literature that otherwise would be lost (Dixon-Woods et al., 2005).

Data Extraction

A data extraction tool was developed to screen and review the relevant articles (Appendix C). The study's author(s), aims, participant characteristics, health condition(s) investigated, methodology and measures, the main findings, the quality score and common themes were recorded for each study.

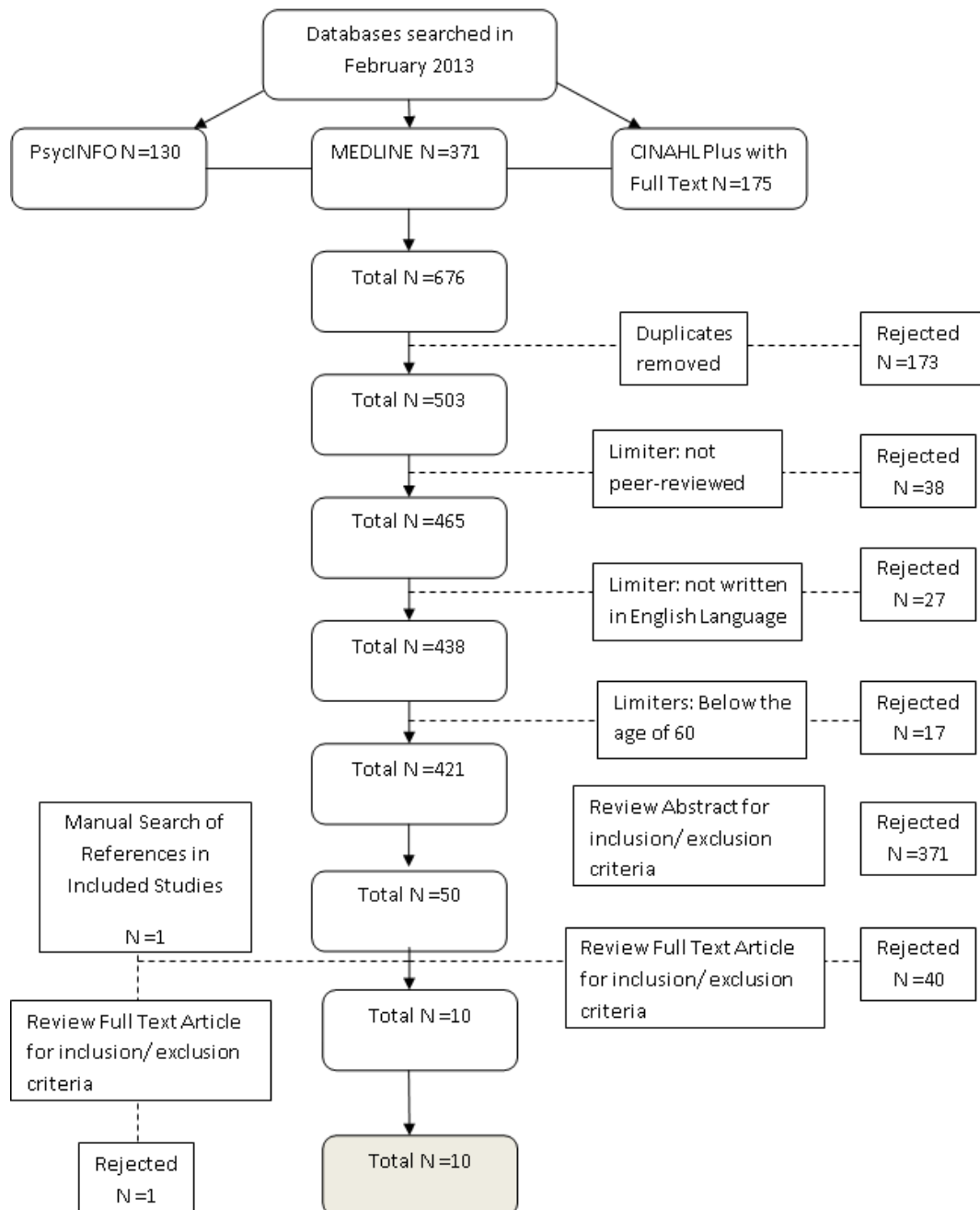


Figure 1. A flowchart illustrating the article selection process.

Results

Characteristics of included studies

The methodological details, the main findings and the quality scores of the ten studies included in the review are illustrated in *Table 1*. All of the studies implemented quantitative methods apart from the study by Grzywacz et al. (2011) which employed a mixed design with both quantitative and qualitative methods. The designs for the quantitative studies were; cross-sectional (N =5), longitudinal (N =1), cross-sectional with multiple regression (N =1), within-subjects analysis of variance (ANOVA) (N =1) and latent analysis (N =1). The mixed method study used semi-structured interviews coded using a systematic computer assisted approach for the qualitative section and latent class analysis for the quantitative section. Eight studies were conducted in the United States of America (US), one was conducted in the United Kingdom (UK) and one was conducted in Germany.

There were a total of 1154 participants in the included studies. The health conditions that were investigated were; diabetes (N =3), osteoarthritis (N =1), mild cognitive impairment (MCI) (N =2), cardiovascular disease and myocardial infarction (N =2). The study by Schüz et al. (2012) investigated illness representations in individuals with multiple conditions including osteoarthritis, diabetes, hypertension, congestive heart failure and chronic obstructive pulmonary disease while Hampson and Glasgow (1996) investigated both diabetes and osteoarthritis.

Seven out of the ten studies in this review employed five different standardised measures to study illness representations which are outlined in *Table 2*. One study employed thematic questions (Gump et al., 2001), one study employed both thematic questions and standardised measures (Grzywacz et al., 2011) and one study employed a

novel card-sorting task to investigate illness representations (Hampson and Glasgow, 1996).

Table 1. The methodological details and the summary of the findings of the studies, including quality scores (QS). The measures used for investigating illness representations appear in **Bold**.

Author(s), Date and Country of Origin	Study Aims	Health Condition	Participant Characteristics	Design	Measures	Main Findings & Quality Score (QS)
Grzywacz et al. (2011); US	Explore the CSMIR holistically and investigate its importance in managing diabetes.	Diabetes	<i>Qualitative:</i> N =74 Age: 60+ <i>Quantitative:</i> N =95 53.2% Female Mean Age = 73 (SD = 7.9)	<i>Qualitative analysis:</i> Systematic computer-assisted approach <i>Quantitative Analysis:</i> Latent Class Analysis and one way analysis of	<i>Qualitative:</i> In-depth interviews (Topics: <i>symptoms, cause, consequences,</i> information seeking, management, medical management and state of mind) <i>Quantitative:</i>	<i>Qualitative:</i> Three discrete CSMIR of Diabetes (causes, symptoms, consequences, management) were identified: 1. Biomedical CSMIR 2. Integrated or Folk CSMIR 3. Fragmented CSMIR <i>Quantitative:</i> Four classes of coherent CSMIR of diabetes were

				variance (ANOVA) for glucose level	<i>Common Sense</i> <i>Model of Diabetes</i> <i>Inventory</i> Glycemic Control (A1C)	identified that were similar to the findings in the qualitative component of the study. A biomedical CSMIR achieved lower non- significant glycemic control QS = 66%
Grywacz et al. (2012); US	Investigate the role of culture in relation to illness representations of diabetes in three ethnic groups (African American, American Indian and Whites)	Diabetes	N =593 38.3% Females Age Cut-off = 60+	Quantitative Cross- Sectional	<i>Common Sense</i> <i>Model of Diabetes</i> <i>Inventory</i>	Illness representations were similar among all three groups particularly for perceived symptoms and consequences. Some illness representations varied as a function of ethnicity but these differences were more prominent for specific educational groups. Education was a better

predictor than ethnicity for variations in illness representations.

QS = 76%

Gump et al (2001); US	Investigate differences in illness representations as a function of age and how these representations predict follow-up health behaviours	Coronary Artery Bypass Surgery	N =309 ‘60 – 68 years old’ (N =108) Age: 64.81 (SD = 2.52) 73.1% Male ‘69 – 86 years old’ (N =98) Age: 73.56 (SD = 3.56)	Linear trend analysis, Chi-square analysis, Factor Analysis and ANOVA	Interviews (cause, course, perceived control), health behaviours	Older adults were more likely than younger participants to attribute the cause of their condition to old age and less likely to identify heredity, health damaging behaviours, emotions and health protective behaviours such as diet as the cause of the condition. Also older adults more likely to believe that they had no control over their condition and that
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						surgery would cure the condition.
						QS = 82%
Hampson and Glasgow (1996); US	To explore and compare diabetes patients' and osteoarthritis patients' implicit illness representations and level of knowledge of diabetes and osteoarthritis	Non-insulin dependent Diabetes and Osteoarthritis	<i>Osteoarthritis:</i> N= 81 74% women; Mean Age = 70.7 (SD = 6.6) <i>Diabetes:</i> N =78 62.8% women Mean Age = 69.6 (SD = 6.7)	Quantitative Within subjects ANOVA	Card Sorting Task adapted from words in the <i>Personal Models of Diabetes Interview (PMDI)/ Personal Models of Arthritis Interview (PMAI)</i>	The group demonstrated more expertise in relation to their own illness than that of the condition they were not diagnosed with. QS = 71%
Hampson,	Investigate	Diabetes	N =78	Quantitative	<i>Personal Models</i>	All personal model

Glasgow and Foster (1995); US	whether personal models (illness representations) of diabetes can predict self-management and glycemic control	57% Females Mean Age = 69.7 (SD = 6.5)	Longitudinal	<i>of Diabetes Interview (PMDI)</i> Profile of Mood States (POMS) General Health Survey (GHS) Short Form Summary of Diabetes Self Care Scale Glycared hemoglobin - Abbot Diagnostics	constructs investigated were correlated with aspects of quality of life and negative affect. Beliefs about treatment effectiveness predicted dietary intake and physical activity QS = 79%
Hampson, Glasgow and	Describe personal models (illness	Osteoarthritis N= 61 72% female;	Quantitative Cross-	<i>Personal Models of Arthritis</i>	Most participants perceived their condition as chronic,

Zeiss (1994); US	representations) of osteoarthritis and investigate associations with self-management and quality of life.		Mean Age = 72 (SD = 7.8)	Sectional	Interview (PMAI)	incurable but controllable though treatment.
					Medical Outcomes	
					Study General Health Survey (Short Form)	Illness representations were related to outcomes: Higher symptoms were related to higher levels of self- management, increased utilisation of medical services and poorer quality of life
					General Health Survey (Short Form)	
					Summary of arthritis management methods (SAMB)	QS = 91%
Lin, Gleason and Heidrich (2012)	Describe illness representations held by people with a diagnosis	Mild Cognitive Impairment	N =30 20 % Female Mean Age:	Quantitative Cross- sectional	The Illness Perception Questionnaire adapted for MCI	MCI was viewed as a serious, chronic, but predictable and controllable condition. The majority of

of Mild Cognitive Impairment (MCI)	76.97 (SD =7.21)	(IPQ-MCI)	participants reported high coherence and low emotional distress.
Investigate the associations of these illness representations with health and socio-demographic variables	Age Range = 60 – 87	Health History: Wisconsin Longitudinal Study	There were associations between the CSMIR domains namely negative consequences, chronic timeline, emotional distress, lower personal and treatment control and emotional distress.
		Demographic Information	
		Mini Mental State Examination (MMSE)	
		Geriatric Depression Scale	Illness representations were associated with socio-demographic variables, depression symptoms and MMSE scores.
		Profile of Mood States (Short Form)	
			QS = 94%

Lin and Heidrich (2012), US	Describe Illness representations and Coping in older people with a diagnosis of MCI.	Mild Cognitive Impairment	N =63 47.6% Male Mean Age = 81.16 (SD 8.31)	Quantitative Cross-Sectional	Illness Perception Questionnaire– adapted for MCI (IPQ-MCI)	MCI was perceived as a chronic but controllable condition. There was diversity in reported consequences, emotional representation and coherence.
	Examine the relationship between illness representations and coping with MCI.				Brief COPE Self-care behaviours checklist Geriatric Depression Scale Montreal Cognitive Assessment (MoCA) Older Americans	Higher perceived symptoms and negative beliefs were associated with significantly more negative consequences, a cyclic timeline and more negative emotional impact. Participants with fewer perceived symptoms and more positive beliefs were significantly more likely to

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engage in coping strategies.

QS = 88%

Schüz et al. (2012), Germany	Investigate illness specific and personal level factors in illness representations using an hierarchical framework based on Cognitive Theory	Multiple Chronic Illnesses	N =305 41.7% female Mean Age = 73.3 (SD = 5.1)	Multilevel regression	<i>Brief Illness Perception Questionnaire</i> General Efficacy Scale Charlson Comorbidity Index Functional Comorbidity Index	Illness-specific representations of timeline predicted personal and treatment control Treatment control was predictive of personal control. Self-efficacy was predictive of personal control QS = 97%
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Tolmie et al. (2001); UK	Compare illness representations, quality of life, anxiety and depression between groups with different levels of attendance in a cardiac rehabilitation programme	Myocardial Infarction; Vascular Disease	N =31, 48% Female Mean Age =74.5 (SD = 6.2)	Quantitative Cross-Sectional	<i>Revised Illness Representations Questionnaire (IPQ-R)</i>	Non-attendees had lower personal control than attendees and females had higher treatment control than males QS = 76%
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Table 2. A description of the measures of illness representations employed by the studies

Questionnaire or measure	Description
The Revised Illness Perception Questionnaire (IPQ-R) (Moss-Morris et al., 2002)	Assesses the domains of the CSMIR: Identity, consequences, chronic timeline, cyclic timeline, personal control, treatment control and coherence. The measure can be adapted for different illnesses.
Brief Illness Perception Questionnaire (Broadbent et al., 2006)	Shorter version of the IPQ assessing the CSMIR domains of illness identity, personal control, treatment control, timeline, consequences, coherence and emotional representations.
Common Sense Model of Diabetes Inventory (CSMDI) (Grzywacz et al. (2011)	Comprises of 94 items measuring beliefs about the cause, symptoms, consequences and medical management of diabetes.
Personal Models of Diabetes Interview (PMDI) (Hampson et al., 1990; 1995)	Assesses beliefs about symptoms (illness identity), cause, personal control, perceived treatment helpfulness (treatment control), feelings towards treatment and perceived seriousness of diabetes
Personal Models of Arthritis Interview (PMAI) (Hampson et al., 1994)	Assesses beliefs about symptoms (illness identity), cause, personal control, treatment control and seriousness of osteoarthritis.

Synthesis

A narrative synthesis of the findings identified three themes: ‘associations between the constructs of the CSMIR’, ‘variables associated with illness representations’ and ‘coping and health outcomes’. The theme ‘variables associated with illness representations’ consisted of four subthemes namely ‘medical variables’, ‘knowledge and understanding of the health condition(s)’, ‘socio-demographic variables’, and ‘person-related variables’. The themes and subthemes were generated through identifying and synthesising repeated patterns and topics in this literature (Dixon-Woods et al., 2005).

Associations between the constructs of the CSMIR

Five studies explored correlations between the components of the CSMIR (Hampson et al., 1994, Hampson et al., 1995; Lin et al., 2012; Lin and Heidrich, 2012; Schüz et al., 2012). Three of these studies found that holding negative illness representations for the health condition in one domain of the model made it significantly more likely to hold other negative illness representations across other domains (Lin et al., 2012; Lin and Heidrich, 2012; Schüz et al., 2012).

Lin et al. (2012) investigated 30 older people’s illness representations of MCI and their associations with demographic variables and health variables. People who perceived MCI to have more negative consequences were significantly more likely to have more negative emotional representations ($p = 0.027$) and perceive the condition to have a more chronic timeline ($p = 0.016$). A more chronic timeline was in turn significantly related with more negative emotional representations ($p = .004$) and less perceived personal control over the condition ($p = 0.016$).

Another study by Lin and Heidrich (2012) investigated illness representations in 63 older people with a diagnosis of MCI using cluster analysis. Three clusters were formed varying significantly on the illness identity scale ($p < .001$). Participants with more perceived symptoms of MCI and more negative beliefs were more likely to have negative emotional representations ($p < .003$), believe that MCI has more negative consequences ($p = .007$) and an unpredictable timeline ($p = .022$).

Schüz et al. (2012) also found associations between negative illness representation constructs in their sample of older people with multiple health conditions ($N = 305$). Negative emotional representations namely higher emotional distress was significantly associated with lower personal control beliefs ($p < .001$). In contrast to the study by Lin et al. (2012), Schüz et al. (2012) found that people reporting a more chronic timeline for their health conditions were significantly more likely to report higher personal and treatment control ($p < .001$ and $p < .001$).

Associations between positive and negative illness representations were also reported by Hampson et al. (1994). The study found a significant correlation between the perceived cause of osteoarthritis and the perceived helpfulness of treatment ($p < .05$). People who attributed the causes of their condition to their own actions were more likely to perceive the condition as more under control with self-management strategies.

Two studies reported positive associations between treatment control and personal control (Lin et al., 2012; Schüz et al. (2012)). Schüz et al. (2012) found that higher personal control scores were positively associated with higher treatment control and vice versa ($p < .001$ and $p < .001$ respectively). Similarly, Lin et al. (2012) found that perceiving treatment for MCI as more helpful was significantly associated with

increased personal control ($p = .004$). The study did not find any other association between the CSMIR constructs (Lin et al., 2012).

Variables associated with illness representations

Medical Variables

Four studies found that medical variables including the duration, symptoms and medical management of the health condition influenced illness representations (Hampson et al., 1994; Hampson et al., 1995; Lin and Heidrich 2012; Lin et al., 2012). The duration of a health condition, defined as the time since diagnosis was reported by three studies (Hampson et al. 1994; Hampson et al., 1995; Lin and Heidrich, 2012). However one study did not find any associations between the actual duration of the condition and illness representations (Lin et al., 2012).

Hampson et al. (1994) found that a longer duration of osteoarthritis was significantly associated with a stronger illness identity ($p < .01$) but was not related to illness representations related to cause, personal and treatment control. Hampson et al. (1995) also found a significant association between the duration of diabetes and perceived cause. A longer duration of the health condition was significantly associated with higher beliefs about personal responsibility in causing diabetes ($p < .05$). However time since diagnosis was not significantly related to beliefs regarding treatment (Hampson et al., 1995). Finally, Lin and Heidrich (2012) found that a longer time since the diagnosis of MCI was related with better understanding or coherence about the condition ($p = .031$).

Actual symptoms, was the second medical variable associated with some constructs of the CSMIR. Actual symptoms are different to the perceived symptoms or

the illness identity domain of the CSMIR construct and refer to symptoms recorded through medical records or medical questionnaires. Older people with more actual symptoms were more likely to have negative illness representations whereas people with less actual symptoms were more likely to have more positive illness representations (Hampson et al., 1994; Lin et al., 2012). In the study by Lin et al. (2012) older people with MCI who had lower cognitive symptoms as recorded by the MMSE were significantly more likely to have positive beliefs about treatment control ($p = 0.002$). Along similar lines, older people with osteoarthritis who had pain in more joints and pain in both knees were more likely to have a stronger illness identity ($p < .05$) (Hampson et al., 1994). In contrast, the study by Lin and Heidrich (2012) did not find any significant relationships between actual symptoms of MCI determined by Montreal Cognitive Assessment (MoCA) score and illness representations. Similarly, Hampson et al. (1994) found no associations between actual symptoms and illness representations regarding personal and treatment control and cause.

The final medical variable implicated with illness representation was medical management of the health condition, which was reported by two studies (Hampson et al., 1994; Lin and Heidrich, 2012). Lin and Heidrich (2012) found that people receiving treatment from primary clinics had a more cyclic and thus more unpredictable timeline beliefs about their MCI than people receiving support from a memory clinics ($p = 0.006$). Furthermore, Hampson et al (1994) found that more visits to the doctor were significantly correlated with a stronger illness identity ($p < .05$).

Knowledge and understanding of the Health Condition

Three studies found that the level and type of understanding regarding the health condition and the sources of information sought for that understanding were related to illness representations (Gryzwacz et al., 2011; Hampson and Glasgow, 1996; Hampson et al., 1994). The study by Gryzwacz et al. (2011) identified that older diabetes patients organised illness representations holistically in three different types of CSMIR. The first CSMIR was a 'biomedical model' comprised of biomedical beliefs about the causes of diabetes and glucose variations, medical consequences and associated management strategies. The second was an 'integrated non-biomedical model or folk model' and was characterised by folk beliefs like managing glucose levels by a meat free diet, believing that stress causes diabetes or using somatic symptoms as indicators for using insulin. The third CSMI was a 'fragmented illness representation model' of diabetes characterised by a mix of beliefs from the biomedical and folk models. The group with a biomedical understanding had a lower but non-significant glycemic level, meaning that they achieved better health outcomes.

Hampson and Glasgow (1996) also investigated variables relating to the understanding and knowledge of health conditions using a novel card sort task designed to explore implicit aspects of illness representations not traditionally captured by health questionnaires. . The findings revealed a significant interaction between patient groups and card sort ($p < .01$), meaning that participants showed more knowledge and expertise about their own health condition compared to the condition of the other group. Finally, Hampson et al. (1994) found that consulting multiple sources of information for understanding the health condition was associated with a stronger illness identity defined by more perceived symptoms attributed to osteoarthritis and more positive beliefs about treatment helpfulness ($p < .05$ for both).

Socio-demographic Variables

Socio-demographic variables including gender, age and socioeconomic and cultural factors were also associated with illness representations as reported by six studies (Hampson et al., 1994; Hampson et al., 1995; Gump et al., 2001; Tolmie et al., 2009; Lin et al., 2012; Grywacz et al., 2012). In general, older women appeared to have more positive illness representations than men. Tolmie et al. (2009) found that women with myocardial infarction reported significantly greater treatment control ($p = .04$) than men. The study did not find any other statistically significant associations between gender and illness representations. Similarly, Hampson et al. (1994) also found that women with osteoarthritis had more positive beliefs treatment helpfulness than men ($p < .01$). However, the study did not find associations between gender and illness representations regarding causes, perceived symptoms and personal control.

Hampson et al. (1995) found that females were significantly more likely to engage in physical activity for managing their diabetes if they had more positive beliefs about their treatment ($p < .04$ and $p < .05$). Older women were also significantly more likely to report better dietary control if they had lower perceptions of responsibility for causing their diabetes ($p < .05$, for both) (Hampson et al., 1995). In contrast, Lin et al. (2012) found that men with MCI had significantly more positive personal control than women ($p = .004$).

Two studies have found an association between age and illness representations (Hampson et al., 1994; Gump et al., 2001). Gump et al. (2001) investigated illness representations as a function of age in patients with coronary heart disease before and after surgery. Participants were divided into three age groups and were compared in terms of their illness representations and health behaviour change. With increasing age

participants were more likely to believe that their condition would be cured following surgery ($p < .0001$) and were marginally less likely to report that they were in control of their condition. Similarly, Hampson et al. (1994) found that older participants with osteoarthritis were significantly more likely to rate their treatment as more useful ($p < .05$). Gump et al. (2001) also found that participants in the older age groups were also more likely to attribute the cause of their condition to old age ($p < 0.001$) and less likely to attribute it to heredity ($p < .001$), health damaging behaviours ($p < .001$), emotions ($p < .05$) and lack of health protective behaviours like diet ($p < .05$). Interestingly, the study found that older people were significantly less likely to report health changing behaviours after surgery compared to younger patients. ($p < .0001$). However, two studies did not find a relationship between illness representations and age (Hampson et al., 1995; Lin et al., 2012).

Finally, socioeconomic and cultural variables including occupation, annual income, education and ethnicity are also associated with illness representations (Hampson et al., 1994; Lin and Heidrich, 2012; Grywacz et al. 2012). Grywacz et al. (2012) found that regardless of ethnic background, older people with diabetes have similar beliefs regarding the causes, symptoms, medical management and consequences of diabetes. Instead, education was a better predictor of disparity between the groups. Similarly, Lin and Heidrich (2012) found that higher education was associated with better perceived understanding or illness coherence of mild cognitive impairment ($p = .002$).

Lin and Heidrich (2012) found that people with a diagnosis of MCI with a higher annual income and who lived with a partner were more likely to perceive their condition as significantly more chronic ($p = .001$ and $p = .008$). The study by Hampson et al.

(1994), revealed a significant relationship between lower personal control and living with relatives ($p < .01$). There were no other significant correlations between illness representations and marital status, retirement status, occupational or education level (Hampson et al., 1994; Hampson et al., 1995; Lin and Heidrich, 2012, Lin et al., 2012).

Person-related variables

Person-related variables such as the level of self-efficacy of the individual and alcohol use have also been explored in relation to older people. Schüz et al. (2012) found people with a higher level of self-efficacy had more personal and treatment control ($p < .001$ and $p < .05$, respectively). Furthermore, in older people with more self-efficacy a chronic timeline was more predictive of higher personal control ($p < .001$). A higher self-efficacy also predicted a higher treatment control irrespective of the level of coherence of the health conditions ($p < .001$). Individuals with lower efficacy and less coherence for the condition were more likely to have a lower treatment control ($p < .05$).

Alcohol use has been studied by Hampson et al. (1994). The study revealed that alcohol use was associated with significantly less control over symptoms of osteoarthritis ($p < .05$) but there were no significant associations with beliefs regarding causes, symptoms and treatment (Hampson, 1994).

Coping and Health Outcomes

The relationship between illness representations, coping and outcomes such as; health functioning, quality of life, psychological and social functioning has been investigated by six studies (Hampson et al., 1994; Hampson et al., 1995; Tolmie et al., 2009; Lin and Heidrich 2012; Lin et al., 2012). The constructs of the CSMIR associated

with coping and outcomes were perceived symptoms or illness identity, causes and cure, control and treatment beliefs.

Overall more perceived symptom beliefs or a stronger illness identity was associated with both helpful and unhelpful ways of coping or management and negative health outcomes. These associations were reported in three studies (Hampson et al., 1994; Lin et al., 2012; Lin and Heidrich, 2012). Hampson et al. (1994) investigated self-management activities used to cope with osteoarthritis pain. The study found that symptom beliefs significantly predicted the number of self-management strategies used, with more perceived symptoms resulting in more self-management activities at baseline ($p < .01$ for both) and at 8 month follow-up ($p < .05$ and $p < .01$). Furthermore a stronger illness identity was significantly correlated with health outcomes such as a poorer physical functioning ($p < .05$), poorer role functioning ($r = -0.46$, $p < .01$), lower overall health perception ($p < .01$) and more bodily pain ($p < .01$). However illness identity was not associated with mental health outcomes and social functioning. Along similar lines, Lin and Heidrich (2012) found that older people with MCI with less perceived symptoms were less likely to engage in coping strategies. Specifically, they were significantly less likely to engage in both problem-focused and emotion-focused coping behaviours ($p = .025$ and $p = .003$, respectively) and were less likely to engage in dysfunctional strategies and use memory aids ($p < .001$ and $p = .003$, respectively). Finally, Lin et al. (2012) found that older people with a stronger illness identity had significantly higher depression symptoms ($p = .0015$).

The longitudinal study by Hampson et al. (1995) found an association between the beliefs about the causes of diabetes and various coping strategies and health outcomes (Hampson et al., 1995). People reporting higher responsibility for causing their diabetes

themselves were significantly less likely to engage in physical activity to manage their diabetes at baseline ($p < .04$) but this relationship was not noted at 4-months follow-up. Higher self-responsibility around causes was also significantly related to negative affect ($p < .05$). However, beliefs about causes were not related to quality of life and did not predict blood glucose levels or dietary intake.

The role of perceived cure or control in coping and health outcomes has been reported by two studies (Hampson et al., 1995; Tolmie et al., 2009). More positive beliefs about cure, control and treatment were related with more positive coping and health outcomes while more negative beliefs were associated with more negative coping and outcomes. Hampson et al. (1995) found that positive beliefs about treatment effectiveness were significantly related to dietary intake concurrently ($p < .001$) and at 4-months follow-up ($p < .01$), and level of physical activity concurrently ($p < .001$) but not at 4-months follow-up. Also, beliefs about treatment and control did not predict glucose level (Hampson et al., 1995).

Tolmie et al. (2009) investigated illness representation in relation to rates of attendance at a cardiac rehabilitation programme of patients ($N = 27$) who suffered a myocardial infarction. Comparison between three groups varying in levels of attendance, resulted in no significant differences in illness representations. However, non-attendees personal control scores were significantly lower than that of combined partial or full attendees ($p = .02$).

Additional Findings in Relation to Methodological Quality

The adapted quality checklist (Harden et al., 2004; Vandebroucke et al., 2007; Puyé et al., 2011) was used to assess the methodological quality of all the studies. Overall the studies achieved good quality scores ranging from 66% to 97%, with a mean of 82 % (see Appendix D). The vast majority of the studies presented clearly the background information and aims of the research. All studies had a high quality for the presentation of the key findings and their interpretation but less so for exploring the limitations and generalisability of the findings.

Given that the current review aimed to investigate the relationships between the CSMIR, coping, clinical outcomes and other variables it was important to consider the quality of the studies in relation to the measures and designs used to examine these variables. Most studies lost points because they did not provide a clear description or rationale for the chosen method, design and the measures, interviews and tasks employed. The studies by Schüz et al. (2012), Lin et al. (2012) and Hampson et al. (1994) were the only studies that provided a clear description of the measures used to examine illness representations and other variables. However, out of these three studies only Lin et al (2012) provided a description of the psychometric properties of the measures employed to investigate illness representations and other variables.

Overall, the studies with the highest quality scores were by Schüz et al. (2012), Lin et al. (2012) and Hampson et al. (1994) which provided a succinct background and detailed methodology, results and implications. The study by Schüz et al. (2012) found that self-efficacy was a variable related to positive illness representations of treatment and personal control. The study benefited from a larger participant sample (N = 305) compared to the other two studies. Lin et al. (2012) found associations between a negative illness identity, higher levels of coping and a poorer quality of life whilst

Hampson et al. (1994) reported associations between the CSMIR, socio-demographic variables and clinical outcomes. The results of these studies should therefore be given more weight. Finally it should be noted that most studies used cross-sectional designs thus causality between the variables studied cannot be determined.

Discussion

Overview of the findings

This is the first review examining the CSMIR (Levental et al., 1984) in relation to older people living with various health conditions. The results revealed a number of important areas that have been investigated in the literature to date. The studies in the area have examined associations between the constructs of the CSMIR and the role of the model in relation to illness management and health outcomes. The literature has also investigated how medical variables, socio-demographics, person-related variables and variables associated with illness knowledge may explain disparity in how older people make sense of their health condition. These findings are likely to have important clinical implications and are worthy of further consideration.

The review revealed associations between the constructs of the CSMIR, providing evidence for its holistic nature. In general, older people holding negative illness representations about their health condition in one domain of the model also had negative beliefs in other domains (Lin et al., 2012; Lin and Heidrich, 2012; Schüz et al. 2012). Such associations were noted between identity, timeline, consequences, control and emotional representations (Lin et al., 2012; Lin and Heidrich, 2012; Schüz et al. 2012). Hagger and Orbell (2003) report similar associations in a meta-analytic review of illness representations in the general population. Hence the way older people make sense of their condition may involve similar processes to younger people. On the whole, these findings suggest that addressing negative beliefs and misconceptions may improve how older people make sense of their condition in a comprehensive manner.

The findings of this review provide some evidence for the clinical relevance of the model defined by the relationship of the model with clinical outcomes. The review

found associations between older people's illness representations and coping, health outcomes and psychosocial outcomes (Hampson et al., 1994; Hampson et al., 1995; Tolmie et al., 2009; Lin and Heidrich 2012; Lin et al., 2012). These findings are also in line with the literature in the general adult population (Hagger and Orbell, 2003). Clinically these results partly support the notion that exploring older people's illness representations, targeting misconceptions and facilitating more positive representations is likely to improve coping, psychological wellbeing and health outcomes. The benefits of such interventions have been reported in the general population (Petrie et al., 2002; Theunissen et al., 2003). However, these findings are largely based on cross-sectional studies which do not allow causality to be determined. Thus conclusions cannot be firmly drawn about cause and effect relationships between the CSMIR and clinical outcomes.

A number of other variables were found to be associated with illness representations in older people. Firstly, medical variables appear to be associated with the way older people make sense of their condition (Hampson et al., 1994; Hampson et al., 1995; Lin and Heidrich 2012; Lin et al., 2012). Longer illness duration and higher symptomatology were generally associated with more negative illness representations (Hampson et al. 1994; Hampson et al., 1995; Lin and Heidrich, 2012; Lin et al., 2012). Addressing illness representations in multidisciplinary interventions is of particular relevance to health management in this population. With the growing ageing population more and more people experience multiple health threats characterised by increased symptomatology and chronicity (Marengoni et al., 2011). Furthermore, the results also revealed that specialist services may foster more positive illness representations compared to generic services (Lin and Heidrich, 2012). In the wider literature, there is some debate as to whether specialist services are more beneficial than generic services

(Wolfs et al., 2008; Meeuwssen et al., 2012) thus this finding should be investigated further. Taken together, these findings indicate that the nature of the health condition and associated healthcare management need to be considered alongside other variables when examining older people's illness beliefs.

Another variable that was addressed in the literature and needs to be considered in healthcare interventions is the individuals' overall understanding and knowledge regarding their health condition. The sole experience of an illness seems to enhance individual knowledge about the health condition in this population (Hampson and Glasgow, 1996). However an accurate biomedical CSMIR has more positive outcomes compared to an inaccurate folk CSMIR (Gryzwacz et al., 2011). Thus healthcare providers should examine and target lay misconceptions that older people may hold about their illness. In the case of illnesses that require active symptom management like diabetes an accurate knowledge of the biomedical characteristics of the illness is essential for successful health outcomes (Coates and Boore, 1996; Kim et al., 2004; Heisler et al., 2005).

Socio-demographic and person-related variations also appear to be implicated with older people's illness representations (Hampson et al., 1994; Hampson et al., 1995; Gump et al., 2001; Tolmie et al., 2009; Lin et al., 2012; Grywacz et al., 2012; Schuz et al., 2012). Some of these variables even predicted better health management (Hampson et al., 1995). In general, older women and older people with higher education had more positive representations whilst living with other people was associated with more negative illness representations (Hampson et al., 1994; Tolmie et al., 2009; Lin and Heidrich, 2012; Grywacz et al. 2012). These variations may be important in clinical practice as they may identify people at higher risk of holding negative illness

representations regarding their health condition which may in turn be associated with poorer illness management. However the processes associated with these variations and their associations with health management are unclear at this stage and require further exploration.

Some age-related variations were also noted in the literature; however the findings are rather inconclusive (Hampson et al., 1994; Hampson et al., 1995; Lin et al., 2012; Gump et al., 2001). In relation to age differences, there was one finding that is of particular clinical importance. Gump et al. (2001) found that with increasing age patients with myocardial infarction were more likely to attribute illness symptoms to ageing and less likely to health damaging behaviours (Gump et al., 2001). This is in line with previous research reporting that a large proportion of older people interpret physical symptoms as a sign of ageing (Sarkisian, et al., 2002). These beliefs may account for the low help-seeking behaviour seen in older people (Walker et al., 2001). The study also found that older people were less likely to engage in health protective behaviours following surgery (Gump et al., 2001). This was the only study directly comparing illness representations as a function of age. These illness beliefs and associated behaviours may put older people at high risk of poorer health status and a higher mortality rate. Thus this area should be investigated further.

A person-related variable that may also be of particular clinical relevance is the association between higher self-efficacy and higher perceived controllability across multiple health conditions (Schüz et al. 2012). Psychological interventions targeting self-efficacy are increasingly recognised as integral parts of successful chronic illness management (Coleman, and Newton, 2005). Higher perceived controllability may have a role to play within this process and needs to be further considered. Furthermore self-

efficacy was a factor associated in relation to multiple illnesses, thus interventions enhancing self-efficacy may benefit older people living with multi-morbidity.

Overall the review was mostly successful in addressing its research aims and questions. It synthesised the diverse strands of literature in this area to identify what has been studied to date in relation to the CSMIR and older people with health conditions. A number of variables have been found to be associated with the model in this population which may have a number of clinical implications. The review was also partly successful in determining the clinical relevance of the model defined as the relationship between the model and clinical outcomes. Even though the findings suggest a relationship between these variables the findings are based on correlations and thus causality within this relationship cannot be determined.

Strengths, Limitations and Methodological Quality

The findings of this review should be interpreted in the context of its strengths and limitations. This is the first study that synthesised a diverse strand of research in the area and identified a number of important clinical implications in this population that need to be considered further. A number of health conditions have been investigated in the literature thus some interpretations can be made about the usefulness and generalisability of the CSMIR across different health threats in this population. However other common chronic health illnesses in older age such as dementia, (Wimo et al., 2006) have not been addressed in the literature, thus the usefulness of the CSMIR in relation to these conditions is unclear.

Overall the included studies had good quality ratings. The studies by Schüz et al. (2012), Lin et al. (2012) and Hampson et al. (1994) should be given more weight during

interpretation as they had very high quality ratings (97%, 94% and 91% respectively). However, the good methodological quality of the studies may be due to ceiling effects of the adapted measure. The measure evaluated thoroughly most of the sections of the articles and allowed comparisons of quality across different designs. However the measure did not comprehensively evaluate the results section of the articles. It is possible that this may resulted in non-representative high quality ratings.

The prime limitation of this review is that only ten studies were identified and analysed. This may be a reflection of limited research in the area or it could be due to limitations associated with the search strategy employed. Thus the findings are constrained by the small body of literature and do not allow firm conclusions to be drawn. Further limitations include the diversity of designs and measures employed that prevent more meaningful comparisons to be made. Furthermore, the use of correlations, does not allow causality to be determined. There is also a marked lack of qualitative research in the area that limits the understanding of the processes involved in the way older people make sense of their condition. Additionally, only one study compared differences between older and younger people's CSMIR (Gump et al., 2001) and such comparisons are crucial for identifying age-related differences such as cohort effects. Finally, there were disparities in the definition of old age, with two studies (Schüz et al., 2012; Gump et al., 2001) employing an age cut-off of 65 while the rest employed an age cut-off of 60. This may limit the representativeness of the findings to older people across the 'old age spectrum'. Health threats may be experienced very differently across this diverse group. For instance, people below 65 are likely to have different life demands as they have not reached the age of retirement thus the impact of a health threat on their lives is likely to be different.

Directions for Future Research

There is a large scope for future research in this area as the literature is very limited. Future research could employ more longitudinal designs to examine whether illness representations predict coping and health outcomes in this population. Furthermore, research in the general population indicates that addressing illness representations in healthcare interventions can improve health outcomes (Petrie et al., 2002; Theunissen et al., 2003). Therefore it is important to study further illness representations in older people. There is also a need for looking at the the model in relation to other common conditions in later life such as dementia. Another important area that requires further exploration is direct comparison of the CSMIR between older and younger people in an attempt to identify age-related differences. Last but not least, the CSMIR could be used as a framework for conducting qualitative research in order to gain a better understanding of the processes associated with the experience and sense-making of illness in older people.

Conclusions

The findings of this review suggest that existing literature has investigated a number of key areas in relation to illness representations in older adults. There is some evidence to suggest that there are some similarities in the way older and younger people make sense of their health conditions through illness representations; however there is a need for further research to identify age-related differences in illness representations. Overall the research in this population is limited and there are a number of gaps in the literature that need to be addressed. The CSMIR appears to be associated with the way older people cope with health conditions in later life however further research is needed to explore further the role of the model in clinical settings and multidisciplinary health interventions.

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*Indicates studies included in the review

Part Two

Empirical Paper

The experience of epilepsy in older people: An exploration of illness representations

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Abstract

Objective: The present study explored ways in which older people living with epilepsy experience and make sense of their condition.

Design: Ten people with a diagnosis of epilepsy aged between 67 and 81 years old took part in the study. Semi-structured interviews guided by the Common Sense Model of Illness Representations (CSMIR) (Leventhal, Nerenz, & Steele, 1984) were conducted and the results were analysed using interpretative phenomenological analysis.

Results: Three super-ordinate and eight subordinate themes emerged from the data. The findings revealed that epilepsy was perceived as a powerful chronic condition associated with harrowing experiences. Participants described various processes and experiences associated with epilepsy that resulted in a ‘disconnection’ from their own body, society and the lives they wanted to lead. In direct tension they also described co-existing experiences associated with ‘integration’. Integration was characterised by a need for more acceptance and understanding of epilepsy at an individual and societal level, learning to live with the condition through coping and positive and collaborative relationships. These findings are discussed in relation to the wider literature of epilepsy, health and ageing.

Conclusion: We conclude that the CSMIR can provide a useful framework for exploring the experience of epilepsy in older age.

Keywords: older people; epilepsy; lived experience; illness representations; interpretative phenomenological analysis (IPA)

Introduction

Epilepsy is a neurological disorder characterised by unpredictable seizure activity ranging in severity, cognitive difficulties and psychosocial problems associated with the impact of the condition on the individual's life (Fisher et al., 2005).

The prevalence of epilepsy in people above the age of 60 is higher than in the general population, with the incidence increasing with increasing age (Kotsopoulos et al., 2002). Epilepsy in older age can have a number of challenges including increased mortality (Lhatoo et al., 2001) and difficulties with diagnosis due to the atypical features that can mimic other conditions such as dementia (Brodie, Elder, & Kwan, 2009). Treatment can be more complex for older people compared to younger individuals due to an increased risk of antiepileptic medication side effects, physical health changes associated with normal ageing and the increased likelihood of the interaction of antiepileptic medication with medication for other health problems (Ramsay, Rowan & Pryor, 2004).

Despite these challenges and in contrast to the extensive literature looking at aspects of psychosocial functioning and quality of life of younger adults with epilepsy (see Baker & Jacoby, 2008 for a review), the psychosocial functioning of older people has received little attention. The small existing literature suggests that older people with epilepsy have more impaired quality of life and psychological well-being compared to the general population (Baker et al., 2001; McLaughlin, Pachana, & Mcfarland, 2008; Laccheo, et al., 2008). With a greater perception of stigma, higher seizure frequency, depression and dysthymia, related to poor quality of life and reduced psychosocial well-being in this population (McLaughlin et al., 2008; McLaughlin, Pachana & Mcfarland, 2010). Furthermore, older people with epilepsy display higher levels of anxiety, more

impaired sleep, lower cognitive status and significantly higher depressive symptoms compared to age-matched controls (Haut, Katz, Masur, & Lipton, 2009).

However there is some debate as to whether older people with epilepsy have more impaired quality of life and wellbeing than the rest of the adult epilepsy population (Baker et al., 2001; Laccheo, et al., 2008). A qualitative study by Martin et al. (2005) found that older people's concerns about living with epilepsy were very similar to that of younger people with driving and medication side effects being frequently reported and rated as the most important concerns. Interestingly, Pugh et al. (2005) report a more favourable health status profile for older people compared to middle-aged adults with epilepsy. The authors suggest that older people may be more resilient and have less social demands placed on them compared to middle-aged adults. They also suggest that there is bigger disparity between younger adults' health status and that of their peers. Whereas, the social comparison in older people may not show this disparity as older people without epilepsy may also experience other health difficulties in later life (Pugh et al., 2005).

Despite these findings there are differences noted in the psychosocial functioning of older people with epilepsy compared to younger populations. For instance, older people report more antiepileptic medication side effects which impact on their quality of life (Baker et al., 2001). Baker & Jacoby (2000) propose that seizures in older age may have different implications compared to younger people. The authors suggest that seizures can have immediate adverse consequences for older people including discomfort, embarrassment, incontinence, hospitalisation and neurological dysfunction. They also suggest that older people may face longer-term effects including loss of confidence and self-esteem, fear of death, fear of subsequent seizures and injury, loss of

functional independence, changes in relationships and anxieties around medication side effects (Baker & Jacoby, 2000). Of particular interest is the finding that older people diagnosed with epilepsy after the age of 65 have poorer psychological well-being and are more anxious and depressed than those diagnosed before the age of retirement (Baker et al, 2001). This implies variations in wellbeing within the older adult epilepsy population that may coincide with other aspects of ageing such as retirement, bereavements, co-morbidity and loss of role functioning.

These findings suggest that the psychosocial wellbeing of older people with epilepsy is poorer than the general population but to date it is unclear whether they are similar to the rest of the epilepsy population. However these findings are confounded by the limited research in the area, methodological limitations including small samples (i.e. Laccheo, et al., 2008; Haut et al., 2009) and the absence of control groups in some studies (i.e. McLaughlin et al., 2010). Moreover, the measures used in quantitative studies are developed and validated for the general epilepsy population and therefore may miss specific issues and concerns of older people (Baker and Jacoby, 2000). There is also a significant gap in the literature in terms of qualitative research. The only qualitative study in the area used a very structured analysis which restricted the exploratory nature of the enquiry and thus limited the richness of results (Martin et al., 2005).

In health psychology there is an increasing emphasis on the importance of exploratory qualitative research in understanding the lived experience and sense making of health conditions that could in turn be used to guide future research and health interventions (Brocki & Wearden, 2004). Interpretative Phenomenological Analysis (IPA) is a qualitative method that explores the phenomenology or individual experience

of different phenomena and is frequently used in health psychology to explore the processes involved in experiencing health conditions (Smith, Flowers & Larkin, 2009). IPA aims to understand and interpret how people make sense of their experiences through the use of language and is increasingly considered as a very important method for exploring sense-making in illness (Smith et al., 2009; Brocki & Wearden, 2004).

Several IPA studies that explored the experience of health conditions have employed the common-sense model of illness representations (CSMIR) (Leventhal, Nerenz, & Steele, 1984; Leventhal et al., 1997) as a framework for conducting semi-structured interviews in order to get an insight into how people understand and appraise their condition (i.e. Green, Payne, & Barnitt 2004). The CSMIR (Leventhal et al., 1984; Leventhal et al., 1997) proposes that people form illness representations or cognitive constructs from a range of sources and existing health and illness beliefs in an attempt to make sense of their condition. The model consists of five components: *identity* refers to personal beliefs about the symptoms, diagnosis or label; *cause* refers to beliefs about the cause of the condition; *timeline* refers to personal beliefs about the condition's duration, *consequences* refers to the perceived implications of the condition and *cure or controllability* refers to representations of perceived cure or controllability of the condition (Leventhal et al., 1984). The CSMIR has been extensively applied to a number of conditions and has been found to play a role in a range of psychological outcomes including coping, well-being, and treatment adherence (Moss-Morris et al., 2002; Hagger & Orbell, 2003). In the general epilepsy population, illness representations have been associated with psychosocial functioning, coping and adjustment where more negative illness representations and strong illness identity were associated with a negative coping and poor adjustment (Kemp, Morley & Anderson, 1999). To date no

studies have explored the illness representation model in relation to older people with epilepsy.

The current study employed an IPA approach and aimed to explore the lived experience of epilepsy in older age, using the CSMIR as a guiding framework. The aim of the study is to explore the processes and the ways in which older people with epilepsy make sense of and experience their condition.

Method

Participants

Ten patients receiving care from a Neurosciences Department in the North of England took part in the study. Eleven participants were initially interviewed but one participant decided to withdraw from the study and was therefore not included in the analysis. It was felt that data saturation was reached with ten participants. All participants were above the age of 65 and were fluent in English. Patients were not invited to participate if they had a self-reported diagnosis of dementia, a learning disability, a serious co-existing terminal physical condition or a serious disabling mental health condition that they felt would influence their ability to talk about their epilepsy. All participants had a confirmed diagnosis of epilepsy from a Neurologist and had experienced at least one seizure in the last two years. *Table 1* outlines the participants' demographic details. Participants identified themselves as White British (N = 9) and White English (N = 1). Most were unsure about the type of epilepsy they were diagnosed with (N = 6) two identified it as temporal-lobe epilepsy, one as post-encephalitis epilepsy and one as petit mal. All participants reported that they were taking at least one antiepileptic medication (range 1 to 3 medications) and nine

participants reported experiencing at least one other co-existing health condition in addition to epilepsy (range 1 to 5 conditions).

Table 1: Self-reported demographic information and age at diagnosis

Participant Number	Pseudonym	Age	Gender	Approximate age at diagnosis
1	'Beth'	73	F	71
2	'Ella'	69	F	22*
3	'Alfred'	81	M	52
4	'Jennifer'	72	F	69*
5	'Ian'	70	M	50
6	'Christine'	73	F	63
7	'Carol'	68	F	38
8	'Sarah'	67	F	28*
9	'Susan'	69	F	21*
10	'Alan'	76	M	71*

*Had undiagnosed seizures prior to diagnosis, predominantly in childhood/adolescence

Design and Procedure

This was a qualitative design which employed semi-structured interviews. The interview schedule included an introductory statement and six questions, five of which were guided by the CSMIR (Leventhal et al., 1984; 1997) and another open-ended question aiming to explore any themes not addressed by the CSMIR (Appendix F). The CSMIR can be a useful framework for guiding interviews in qualitative research and particularly IPA as it has an important role in sense making of health conditions

(Leventhal et al., 1984). The aim of IPA is to explore how individuals interpret and make sense of experiences like health conditions (Smith et al., 2009) which is in line with the foundations of the CSMIR. Thus the use of the model as a guiding framework can elicit participant's interpretations and sense-making of their epilepsy.

The interview was validated by a member of the direct clinical care team who obtained feedback from two older patients with epilepsy. The clinician and the participants expressed that the questions felt appropriate. Ethical approval was secured by the local Ethics Committee (Appendix G). Patients who met the inclusion criteria were identified by members of the clinical care team and approached either during routine clinics (N = 3) or sent an invitation and information sheet (Appendix H) by post (N = 7). Overall 32 patients were approached, 3 in clinic and 29 through a letter invitation. Patients who agreed to take part were initially contacted by the researcher and a convenient meeting was arranged either at the hospital or the participant's home. Initially the researcher obtained written informed consent (Appendix I) and the demographic questionnaire (Appendix J) was completed with the participant. This was followed by the semi-structured interview lasting on average 57 minutes (range 38 to 79 minutes). Participant anonymity was protected by assigning pseudonyms during data analysis and write-up.

Data Analysis

The interviews were digitally recorded and transcribed verbatim and analysed using IPA methodology as described by Smith et al. (2009) (see Appendix K for Epistemology Statement) . The data for each participant was analysed through careful reading and re-reading of interview transcripts, writing initial thoughts and comments and eventually identifying central themes (see Appendix L). Common themes and

associated verbatim identified for each participant were explored for connections between participants to develop salient subordinate themes across participants. Initial narratives for each subordinate theme were developed with the supported verbatim and connections between the subordinate themes were noted to develop the super-ordinate themes. During data analysis the CSMIR and its constructs did not guide the analysis and extraction of themes because IPA aims to explore individual experiences without making previous assumptions or building on existing research (Smith et al., 2009). Therefore data analysis aimed to extract themes based on participant's accounts and individual experiences rather than previous theory or previous research.

Quality and Validity

To ensure credibility, the second author followed all the steps of the analysis process from the individual transcript analysis through the final analysis across all interviews, where any questions arose about categorisation of themes was discussed until an agreement was reached. An IPA group of four researchers familiar with conducting IPA also examined and re-examined accounts and themes in order to help review and refine thematic headings. A central focus of validation was making sure that the themes identified were grounded and supported by the participants' verbatim. Smith et al. (2009) argue that there is no prescriptive number of participants that need to support a theme to ensure validity as the aim of IPA is to prioritise the voice of the individual. For the purpose of this study themes were developed if they appeared to resonate across accounts and the results highlight themes that appear more popular or salient. However no theme was excluded if it was not represented across the majority of the accounts as the aim of IPA is to capture the individual's experience.

Results

Three super-ordinate themes and eight subordinate themes emerged from the analysis. *Figure 1* illustrates the themes and the associations between them. In brackets is the number of participants that supported each theme. As illustrated in *Figure 1* ‘*The Power of Epilepsy*’ was a super-ordinate theme that dominated the whole experience of epilepsy. It was felt that the power of the condition was a driving force that was causing tensions between the two other contrasting coexisting super-ordinate themes ‘*Disconnection*’ and ‘*Integration*’.

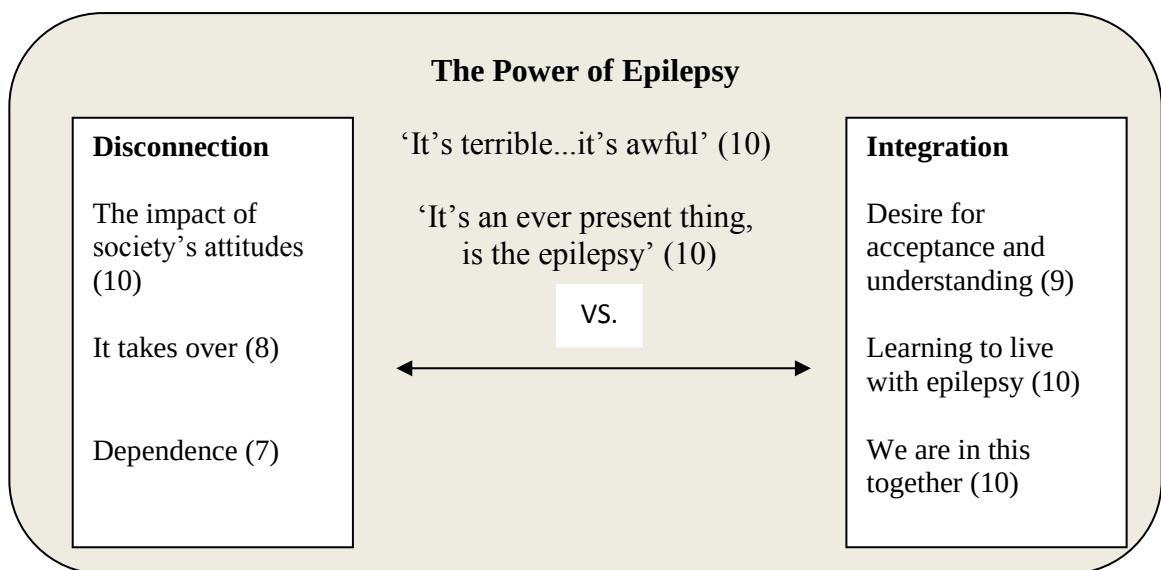


Figure 1: The super-ordinate and subordinate themes and the associations between them. In brackets is the number of participants supporting the theme.

The Power of Epilepsy

Throughout all the participants’ accounts there was an overarching theme reflecting the power that epilepsy had in the lives of the participants and others around them. Epilepsy was often referred to as ‘it’ and at times the condition was described as a separate threatening and unpredictable entity that was waiting to attack the person at every opportunity. Two subordinate themes named after participant’s descriptions

represented the two dimensions of this super-ordinate theme: *'It's terrible....it's awful'* and *'It's an ever present thing, is the epilepsy'*.

'It's terrible....it's awful'

All participants described distressing and horrific experiences caused by the epilepsy. For most participants there was an apparent threat or risk of injuries or harm caused by seizures. Participants described instances where they suffered very serious injuries and it was often very difficult for them to talk about these experiences during the interview:

'...last September I did that, went over backwards, blacked out and I caught my back of my head, there (Pause) on the pavement stone and I ended up with a cracked vertebra and a fractured skull.' (Christine)

While epilepsy was powerful, participants often described feeling powerless. Many described feelings of vulnerability as they encountered truly horrific situations as a result of seizures:

'I mean the worst experience I can tell you about and I can't I can't forget it, it's no good. (Son's name) was a baby and he was in a pram, I had a carriage pram, a high pram. And I was walking to the shop with me pram and I went into a fit. Or I know I did because when I come around the pram was tipped upside down on its handle bars and (Son's name) was hanging on his rains! But my handbag had gone! But they hadn't pick that pram back and put that baby safe.' (Ella)

The horror and trauma also related to concerns about the impact of epilepsy on other people:

'...they don't want this to happen in front of them. That would be the worst experience they could have I would've thought' (Alan)

Participants also described their own experiences of witnessing others having seizures. Alfred's account illustrates how difficult it was to witness what might be happening to him when he has a seizure:

'There was another person, he would be in his 30's now and I've seen him have fits, once or twice so, yeah when I think it happened to me that, it's, it's awful.' (Alfred)

Sadly, the traumatic experiences described by many participants, were also related to experiences of healthcare and particularly hospitalisations following seizures. Susan describes how the treatment she received in hospital was so traumatic that she is terrified of going back again:

'Well, (sighs) little things like, I couldn't I couldn't walk really. I was in a bed state. I asked someone to take me to the bathroom and of course they were too busy (said in a lower volume), so I finished up on floors, looking for a bathroom.(.....) I, I wouldn't make it if I if I was put in a hospital again.' (Susan)

‘It’s an ever present thing, is the epilepsy’

The power of epilepsy was also related to its chronicity. Often there was an underlying hopelessness surrounding the duration and curability of the condition. Participants viewed epilepsy as a chronic and constant presence in their lives. All participants described that their condition would be with them for the rest of their lives:

‘...it would be something that I will take with me to my grave.’ (Christine)

Participant’s beliefs regarding the chronic duration of their epilepsy were closely related with their beliefs about its curability:

‘As they haven’t been able to control it with drugs until now, for 30 years, I don’t see that they’re going to find any drugs or any level of drugs that are going to cure it completely. So I am expecting it to last for the rest of my life.’ (Carol)

Alfred described the relationship between his beliefs about the duration of epilepsy to his beliefs about ageing:

‘I don’t think I’ll get rid of it now. I am 81, most likely won’t live many more years and eh, I think is going to be there all the time now, yeah.’ (Alfred)

Even when seizures were under control some participants described that epilepsy was still a persistent presence lurking in the background:

'Yes, I haven't had any seizures since I took err these tablets that were recommended but it is there in the background' (Beth)

The nature of the constant presence of the condition was described by many participants as erratic and unpredictable where a seizure was almost waiting to attack them at every opportunity. This unpredictability appeared to cause a lot of fear in anticipation of the next attack which strongly contributed to the power of the condition:

'Yeah, I'm always, not always, but very often I'm looking in the corner and thinking, that feeling I've got is this the beginnings of, of an event. Is that normal, not normal, is that (pause) epilepsy warning or not? So I've always.... It's there I think in my mind with regard to whatever I feel...'
(Alan)

Because epilepsy was a constant and persistent presence, many participants had to consider and plan their lives around the epilepsy and the possibility of a seizure:

'It's there, it has to be taken into consideration, anything we do anywhere we go' (Christine)

Disconnection vs. Integration

There was an overarching theme of disconnection throughout the accounts of all participants. This disconnection was evident across different contexts including a physical disconnection during a seizure and in the period of recovery, a social disconnection and disconnection from the life that participants wanted to lead. However

within and between participants' accounts there was a clear tension between the different contexts of disconnection as there was also an overwhelming need and battle for integration. 'Disconnection' and 'Integration' were two polar opposite themes that were present at the same time. Participants were flipping between these opposing themes throughout their accounts. It was felt that 'The Power of Epilepsy' was causing this dynamic process as people were disconnected because of their harrowing experiences and were actively trying to integrate the condition into different aspects of themselves and their lives. However integration was prevented by the power of the condition resulting in tensions or opposing themes. Three subordinate themes represented the disconnection and three subordinate representing the need and battle for integration. These are presented alongside each other to reflect the tensions evident in participant's accounts.

The impact of society's attitudes

All participants described elements of stigma related to their epilepsy that led to a disconnection from society. Most participants described negative attitudes and a lack of understanding about epilepsy in society:

'...most people have their own ideas about it. They think you're (laughs), you know, crazy and eh, that's awful' (Alfred)

'I suppose, my general impression, how epilepsy is viewed in society. It's something a bit degrading' (Alan)

'it would be better if it was more widely known because it was the kind of thing that if people had it in the 15th and 16th century they would be burnt to the stake from ignorance' (Christine)

For most participants these attitudes and lack of understanding often lead to many experiences of discrimination and social exclusion:

'See I I want, always wanted to be a nurse when I was at school. And that again you see when I went, I did all the school work and that for it and I passed that part of it but when I went to the hospital for an interview for training I just got oh we have enough of patients passing out without the nurses and that upset me.' (Ella)

'Suddenly people in a Christian surrounding, didn't want to have anything to do with you' (Ian)

Consequently, many participants choose to keep their epilepsy concealed and hidden mainly in an attempt to avoid the discrimination and shame inflicted on them.

'...the other residents for example would cross the street to get away from me. Now that, and there and and there and after that happened, I vowed I wouldn't tell anybody' (Susan)

Interestingly, this lack of understanding was also present in the accounts of participants themselves; at times there was a sense that there was a fragmented understanding about their epilepsy:

'I don't know I don't know how it all works' (Jenifer)

For some the concealment appeared to feed into the stigma and lack of understanding.

'I don't speak to people about it so maybe that's the problem' (Alan)

Vs.

Desire for acceptance and understanding

In direct tension with feelings of discrimination and isolation participants described a desire for acceptance and understanding for the condition from society but also for themselves. There was a sense that acceptance and understanding would lead to an experience of integration operating at two levels. The first level was increased acceptance and integration of the individual in society through increased awareness and compassion regarding their epilepsy from the general public and healthcare professionals. Most participants described the need for more awareness in society and the importance of acceptance and integration:

'if they've had these seizures and these collapsing and I think people should be there to help them and err make sure they can live their life normal, or as normal as you can really'. (Jenifer)

Some participants actively reached out for integration in society and tried to escape from the social isolation that epilepsy brought in their lives:

'....I go out of the house and I meet the rest of the world and that in fact is a therapy in itself' (Ian)

The second level of integration was an individual process of acceptance and understanding. Most participants described a process of searching for an understanding

and trying to make sense of their condition through a variety of sources including healthcare professionals, medical investigations and research, social media, self-reflections and talking through their experiences with other people:

‘when you come to terms with epilepsy you come to understand it, by investigation gives you better understanding of it, so I can say I could spend two hours on a computer screen reading up epilepsy which can be a therapy in itself’ (Ian).

Several participants emphasised the importance of having the space to talk about their experiences with the Specialist Epilepsy Nurse as a way of making sense of it:

‘Well, after this epilepsy, these seizures have occurred, if I had some more (Epilepsy Nurse) pastoral care sort of err attention, I think things would have ended sooner and err and I could have been helped there because it would make me analyse what was going on rather than just cope.’ (Beth)

It takes over

Most participants described that epilepsy took over their lives. The most apparent instance where epilepsy took over was during a seizure. Participants described seizures as a disconnection from their environment or an absence from the world where they lose control of their body while epilepsy takes over. Sometimes this was a complete disconnection and loss of control:

'...they got me into the hospital and I was on the trolley, and (husband's name) says you got up, you sat up and you screamed and shouted. I've never, I mean that is not me, not me at all.' (Jenifer)

Other times participants had some conscious awareness of what was happening:

'It was the oddest sensation because I was here while the incident was going on. But it wasn't me that was laid on the floor. And I heard my skull crack on the stone. It sounded like somebody cracking an egg' (Christine)

Most described the aftermath of a seizure as the second instance where epilepsy almost invaded their mind and body often resulting in further feelings of disconnection and isolation.

'..... the worst part of having a seizure is not the seizure itself, that's the bit that's alright, it's afterwards, because when you've had a seizure, your mind your body, everything is a bit like a balloon that's burst. It's so disorientated, you don't know quite where you are, you are not sure of your world or anything like that.... Your physical body literally stops working (...) Because it's as if you had a 100 Volts of electricity pushed through your body' (Ian)

On more of a day to day basis, most participants also described that epilepsy was taking over aspects of their lives. There was an extensive reference to restrictions and losses that participants had to face throughout their lives because of the epilepsy and also because of the impact of their medication:

'It restricts you. They say you can live a normal life but you can't. You can't because you've got to watch so many things that you know affect you for a start.' (Ella)

'But they had me walking around like a zombie. I had all kinds of medicine, two or three, four times a day. It was a case of shake me, I rattle.' (Susan)

Vs.

Learning to live with epilepsy

In direct tension to the subtheme 'it takes over' there was a sense that all participants were finding ways to integrate epilepsy in their lives and learning to live with the condition in the context of the restrictions and the difficulties that they were faced with. This subordinate theme is characterised by a wide range of attitudes and coping strategies that participants' put in place to help them live with the condition. From all the participants' accounts there was a clear sense of resilience and strength. Most participants clearly articulated a determination to manage the epilepsy which in turn helped them find ways of coping with the condition:

'I believe in getting up and getting out and doing what you can.' (Susan)

Some participants tracked their resilience and determination as part of their life story and their legacy:

'It runs in the family and it runs in Yorkshire, sheer bloody-mindedness. It's not stopping me I am going out' (Christine)

Most participants also described how they planned and regulated their everyday activities and at times avoided certain situations as a way of coping with the condition. Some participants described how they managed their condition through self-care. Of particular interest is Ian's account where he describes self-care as a way of coping but at the same time he describes parallels with the context of his life stage and the loss of his wife:

'...I make a very strict regime of my lifestyle, I realise this, and I realised this more when I lost my wife, you've got to always make certain that you keep yourself full of nutrition, you've got to eat well, you've got to live a healthy lifestyle, you've also got to be able to get plenty of sleep, which I suppose is old age at my age at 70 these days but I think you've got to set a plan for your life, you've got to work out a plan of keeping yourself as much physically and mentally a a a alert as well...' (Ian)

Medication was another way of coping that was described by some. This is of particular interest given the conflicting nature of medication as a source of support but also at times as a source of difficulties like side effects:

'I think I have total control now I have this Tegrotol pills. They have taken it away.' (Beth)

Dependence

Dependence was a subtheme described by most participants and was characterised by a reliance on other people and medication. Many participants described a loss of independence because of their epilepsy that lead to a disconnection from the life that they wanted to lead or the life they had previously known. Instead they had to depend on other people particularly their partners to be able to do their everyday activities:

‘Err, as I say I don’t go out alone. So I mean that’s a big thing err I usually do most of my heavy baking like with the oven on when (Husband) is around.’ (Ella)

Not being able to drive was an issue that was raised by most participants. Driving appeared to mark a loss of independence for many participants and relying on other people for transport was often very difficult for them:

‘Not, not being able to drive has been one of the most annoying things, and, so I’ve always had to go via public transport, or have somebody else to drive me. If we are going out with friends then they have to be the drivers and I have to be passenger.’ (Carol)

Some participants also appeared to depend on their partners for explaining their experience of epilepsy as they were unable to recall what was happening to them particularly when they were having a seizure:

‘But if you need to know definitely you must ask (Husband) because he will know. I just don’t, these are things that I don’t remember’ (Jenifer)

Finally, many participants described a dependence on medication where not having their medication caused a lot of uncertainty and fear about recurrent seizures:

'If I forgot to take my tablets I don't know what would happen' (Alfred)

VS.

We are in this together

This subtheme was prevalent across all participants. In direct tension to the theme of 'dependence' this subtheme was characterised by a positive and collaborative connection or integration between the participant and their partners or their epilepsy nurse as a result of the condition. The experience of epilepsy was often a shared experience for most couples who would unite against the condition. Throughout the accounts participants would use 'we' instead of 'I' to describe their experiences. Often there was a very close bond in the couple which was mutual and empowering:

'But we've got each other and that helps, that really does help.' (Beth)

For some, the condition even strengthened their relationship with their partners:

'... I think I am closer with (husband) because of it than I would be probably in an ordinary marriage kind of thing, you know' (Ella)

Many participants invited their partners in the interviews and there was a clear sense that they wanted their partners to be present and share their side of the story. At times they would even finish each other's sentences adding to each other's story:

'it is nice having (husband's name) to sort of, I feel it's nice you can correct me on things I have forgotten, or eh help to explain things more thoroughly.'

(Carol)

Most participants also described a connection with their epilepsy nurse who was often seen as a supportive ally against the condition:

'(Epilepsy Nurse) is my valuable magic Genie in a bottle' (Christine).

They described a collaborative relationship with their epilepsy nurse that was based on trust, mutual respect and a sense of being valued as a whole person rather than just a patient.

'Yeah, you know I can talk to her like I can talk to you or I can talk to him.'

(Sarah)

Interventions planned with the epilepsy nurse were often collaborative and holistic which incorporated medical and psychosocial elements:

'Just having her in the background and on my side (laughs) and really concerned about me getting better, not just controlling the epilepsy, you know. She wants, she wanted, she wants me off these pills she wants me back to what I should be and not taking these these pills.' (Beth).

Discussion

This IPA study employed the CSMIR (Leventhal et al., 1984; Leventhal et al., 1997) to investigate the experience and sense-making of epilepsy in older people living with the condition. The findings have strong links with the wider literature related to epilepsy, ageing and health. The super-ordinate theme '*The Power of Epilepsy*' had a central role in the experience of the condition as it appeared to cause participants to flip between experiences of '*Disconnection*' and attempts for '*Integration*' of the condition into aspects of their lives. The power of the condition prevented such attempts as participants were constantly subject to harrowing experiences. The power of epilepsy was evident in the physically and emotionally horrific and distressing experiences that participants went through as a result of the condition. In the general epilepsy population seizures pose serious and at times life-threatening physical injuries to people living with the condition (Nguyen & Téllez Zenteno, 2009). In this study however, the emotionally distressing experiences associated with social stigma, personal vulnerability and even healthcare experiences appeared to be equally if not more horrific than the physical threats. These experiences may form a strong and threatening illness label of epilepsy which may be difficult to integrate into aspects of identity and autobiography. This could be part of the reason why epilepsy was described almost like a separate entity to the person.

Crossley (2000) suggests that traumatising experiences such as serious and chronic illnesses can cause an 'ontological assault' or 'biographical disruption' in the coherence of narratives of the self, the world, time and everyday 'lived experience'. Story-telling and 'narrative configuration' can be a way to deal with such traumatic events and incorporate them into the person's identity and life story (Crossley, 2000). In the current study such opportunities for story telling were reported as being rather

scarce, when considered in relation to the repeated traumatic events that participants experienced. It is perhaps unsurprising that participants struggled to integrate the condition into their lives.

The chronic timeline, the constant presence and the unpredictability of the condition represented by the subordinate theme '*It's an ever present thing is the epilepsy*' were also components of the power of epilepsy. Findings from the literature on illness representations suggest that viewing a condition as chronic and incurable has a negative impact on coping, health outcomes and psychosocial outcomes (Hagger & Orbel, 2003). Furthermore, the unpredictability of epilepsy described by many participants seemed to create a lot of fear and anxiety. Vasquez and Devinsky (2003) suggest that the volatility of seizures in the general epilepsy population may promote an external locus of control and cause anxiety and fear.

An external locus of control may also be relevant to the subordinate theme '*it takes over*' where participants described different instances of loss of control and disconnections as a result of their epilepsy. This included a loss of control over one's body during and following a seizure, as a result of antiepileptic medication and because of a number of restrictions and losses. Within this subordinate theme there are a number of parallels with ageing which are also related to an external locus of control. Knight's 'contextual, cohort-based maturity/ specific challenge' (CCSC) model suggests that older people face a number of specific challenges including changes in physical health, bereavements and loss of role functioning (Knight, 1996) which are beyond the individual's control. Thus, loss of control over one's body during a seizure may be particularly frightening for an older person as they also face changes in their body due to ageing that they may be unable to control. Furthermore, the restrictions and loss of independence as a result of epilepsy can also be part of the ageing process. Having to

face the parallels between ageing and epilepsy can be particularly challenging and may be related to the impaired psychosocial functioning of older people with epilepsy as has been suggested by Baker and Jacoby (2000).

In direct contrast to the subordinate theme ‘it takes over’ participants described their attempts to integrate the condition in their lives and engage in coping behaviours. These were represented by the subordinate theme ‘*learning to live with epilepsy*’. Both active coping behaviours such as self-care and cognitive means of coping such as social comparison of the health status of age-matched peers were reported. This theme is consistent with the finding that older people derive hope and find positive ways of coping with other chronic neurological conditions such as dementia in an attempt to balance the challenges posed by the condition (Wolverson, Clarke & Moniz-Cook, 2010). Of particular interest is the use of imagery and metaphors by some participants i.e. ‘burst like a balloon’ to describe their experiences. The use of imagery and metaphors may be an attempt to describe the vividness and the emotional valence of their experience. Imagery and metaphors can provide a platform for processing and making sense of distressing experiences. Indeed imagery restructuring has been a successful technique used in cognitive behavioural therapy to reduce emotional distress in trauma (Holmes, Arntz, & Smucker, 2007). In the health literature the use of imagery is a promising strategy in psychological interventions addressing psychosocial and health outcomes (Gruzelier, 2002).

The role of stigma was overwhelmingly represented in the findings particularly within the subordinate theme ‘*the impact of society’s attitudes*’. Stigmatising attitudes, lack of knowledge and understanding existing in society and even within participants themselves lead to social disconnection and exclusion. Most participants described that throughout their lives they were ostracised and discriminated against because of their

epilepsy. Epilepsy has historically been a stigmatising condition with the burden of stigma having a more severe impact on psychosocial functioning than the medical aspects of the condition (Morrel, 2002). Indeed, in older people stigma associated with epilepsy is a predictor of quality of life (McLaughlin et al. 2008). According to Knight's CCMC model older people hold socio-cultural beliefs determined by their generational circumstances which in turn influence how they perceive the world (Knight, 1996). Older people may be more susceptible to stigmatising experiences and beliefs about epilepsy as a result of such cohort effects. Attempts for a shift in negative attitudes surrounding epilepsy is relatively recent (de Boer, Mula & Sander, 2008) thus older people are likely to have experienced more rejection and stigma because of their condition. For instance, until 1970 a law prohibiting marriage in people with epilepsy was in place in the United Kingdom (de Boer et al., 2008).

Furthermore older people may be subjected to more social stigma than their younger counterparts with epilepsy because of 'double stigma' resulting from both age and epilepsy. Older people are often susceptible to negative beliefs about ageing existing in modern technologically-dependent societies that value economic production and perfection and often undervalue older people or see them as a 'burden' in society (Stirling, 2010). Butler (1969) suggests that ageism can result from a fear by younger people of growing old, as it can be a reminder of human mortality. As a result older people are segregated and rejected from society (Stirling, 2010). Stirling (2010) suggests that such stigma and rejection is in turn internalised by older people who feel even more isolated and alienated. This process is almost identical to the stigma and discrimination described in relation to epilepsy in the current study suggesting that these processes may run in parallel perhaps exacerbating feelings of disconnection from

society. Furthermore, older people may also face other socially stigmatised illness in later life such as dementia (Benbow & Reynolds, 2000).

In an attempt to avoid such discrimination and stigma many participants kept their condition hidden and concealed. According to the CSMIR people form illness schemata through a variety of sources of information (Leventhal et al., 1984; Leventhal et al., 1997). Social isolation, disconnection and concealment may hinder opportunities to make sense of the condition. It is noteworthy for example that six participants were unsure about the type of epilepsy they were diagnosed with. This is an indication that older people may not have a coherent understanding of their condition which may in turn lead to poor coping and health outcomes (Hagger & Orbel, 2003). Healthcare providers should therefore explore older people's misconceptions and aim to provide information to older people with epilepsy in an accessible and service-user friendly way. Furthermore concealment may lead to hidden distress related to stigma in older people with epilepsy which may not be captured by existing quantitative measures. Future research should investigate these issues further to facilitate a better understanding and aim to develop measures that capture them.

These findings highlight the need for interventions targeting stigma, discrimination and lack of understanding at an individual level but also at a societal level. This need is also ingrained in the experience of participants in this study and is captured by the subordinate theme '*desire for acceptance and understanding*'. There is a huge scope for increasing awareness of the condition in society and it is important to target negative attitudes existing in the public and in healthcare services. At an individual level the importance of holistic interventions targeting misconceptions

around epilepsy and the psychosocial difficulties surrounding the condition are of particular importance to older people. Even though the current study did not aim to build on existing theory to adapt the CSMIR for this population the findings suggest that the CSMIR can be a useful guiding framework for exploring and eliciting individual's beliefs, experiences and understanding of epilepsy in clinical settings. Using the model flexibly and in an open-ended way can elicit idiosyncratic experiences and beliefs, such as experiences of healthcare that are not captured by questionnaires of the CSMIR. These can in turn be addressed in a person-centred way.

The importance of relationships for older people with epilepsy was illustrated in the opposing themes of '*dependence*' and '*we are in this together*'. These themes highlight the importance of viewing illness as a shared experience between the individual and their immediate social support. The significance of social support and support from partners is increasingly recognised in the general epilepsy population and in other chronic health conditions (Elliot, Charyton, Sprangers, & Moore, 2011; Martire, Lustig, Schulz, Miller, & Helgeson, 2004). Providing support to partners and carers and increasing their understanding of epilepsy may help to diffuse the horror and power of the condition and allow older people and their families to cope more successfully with the condition. Furthermore, healthcare should incorporate holistic and relationship-centred interventions that incorporate the biopsychosocial aspects of epilepsy. Most participants described the value of having a specialist nurse on their side. The nurse was often perceived as a supportive figure rather than just a healthcare professional. Some of the key features to this relationship were; the opportunity to talk about their experiences, the emphasis on psychosocial difficulties alongside medical care, the collaborative nature of the relationship and being reliable and available. The importance of such holistic and specialist continuing care in relation to people with long

term conditions is increasingly recognised within healthcare policies and government initiatives in the UK (House of Commons Health Committee, 2005).

Limitations and Future Work

Interviewing individuals alone is a limitation of the current study given that partners frequently expressed a desire to participate in the research. Future work should investigate epilepsy in older people as a shared experience and interview dyads together to explore this. An investigation into the needs and experiences of carers and family members could also be an important area of future research. Furthermore, the current study looked at the experiences of a culturally homogeneous sample. IPA looks into the phenomenology and lived experience of different events and phenomena. Such phenomena are likely to be influenced by cultural influences so it is also important to investigate further the experience of epilepsy in older people from minority cultural groups. For instance, the notion of stigma may be more prevalent in some cultures which in turn may influence people's experiences (de Boer et al., 2008).

Further limitations and implications are related to the recruitment methods employed in this study. Firstly all participants were recruited from the same clinic; therefore their experiences of healthcare may have been very similar. Furthermore, the study recruited volunteers, mainly through invitations to participate sent through the post. This method of recruitment may be biased to exploring the experiences of people who are prepared or willing to talk about their epilepsy. The experiences of people who are more stigmatised and isolated may not be represented. Future work could employ other methods of recruitment i.e. approaching all patients in clinics. Another area that could be addressed in future research is the impact of age at diagnosis as it may have important implications in the psychosocial functioning of older people (Baker et al.,

2001). Finally, the role of imagery and metaphors in the experience of illness and health is an area that is largely unexplored and future research should address this as there may be important therapeutic implications given that story telling may go some way to helping with the integration of illness experience.

Conclusions

The themes emerging from this study provide an insight into the lived experience of epilepsy for older people. The level of trauma and horror shared in participants' stories was striking and harrowing. Participants were going through a constant battle to move away from the disconnections that they experienced and tried to integrate the condition into aspects of their lives and achieve successful coping. This battle is likely to be moderated by the traumatic nature of the experiences that interrupt coherent narratives of self and the world on one hand and the tremendous resilience and strength of participants on the other hand. It is also important to note the value of other people in participants' experiences both as a source of distress i.e. through stigma and discrimination but also as a source of support i.e. a shared experience in couples. Epilepsy was described as a social condition that was stigmatised and discriminated against and there is a large scope for interventions targeting such stigma in society and with individuals themselves. Finally, there were numerous parallels between the epilepsy experience and ageing, which may exacerbate fear, anxiety and depression in older people living with the condition. All of these findings highlight the importance of holistic biopsychosocial interventions that target different aspects of the experience of epilepsy in later life and allow participants to make sense of their condition. The CSMIR can provide a framework for helping individuals form a coherent understanding of their epilepsy.

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Part Three

Appendices

Appendix A – Submission guidelines for the *International Journal of Psychogeriatrics*

Please read these instructions carefully before submitting articles. Articles which are not prepared in accordance with these guidelines will be returned to authors unreviewed.

Scope and contributions

International Psychogeriatrics is written by and for those doing clinical, teaching, and research work with elderly people. It is the official journal of the International Psychogeriatric Association (IPA) and is published by Cambridge University Press, Cambridge, UK. Although it is concerned primarily with psychogeriatrics, the journal welcomes contributions from all concerned with the field of mental health and aging. Original research papers are particularly sought.

Contributions include original research articles, reviews of the literature, “for debate” articles, case reports, letters to the editor, book reviews and editorials. Apart from editorials, “for debate” articles and book reviews, which are commissioned, contributions to *International Psychogeriatrics* are spontaneously written and submitted by authors. Papers are reviewed by at least two expert reviewers selected by the Editor-in Chief. At present about half of the papers submitted are accepted for publication in this journal which is published twelve times per annum. The journal’s Science Citation Index Impact Factor (2011) is 2.24. Submission of a paper implies that it is neither under consideration for publication elsewhere, nor previously published in English. Manuscripts must be formatted double-spaced with ample margins on all sides and the pages should be numbered. Please leave a spare line between paragraphs to enable typesetters to identify paragraph breaks without ambiguity. *International Psychogeriatrics* uses the spelling of American English. Manuscripts written by those whose primary language is not English should be edited carefully for language prior to submission. *International Psychogeriatrics* has a Language Advisory Panel of English speakers willing to check manuscripts for style prior to submission. Details can be found at both the journal website (<http://journals.cambridge.org/ipg>) under the related links icon and the IPA website (<http://www.ipa-online.org/>).

Submission of manuscripts

Manuscripts should be submitted online via our manuscript submission and tracking site, <http://mc.manuscriptcentral.com/ipg>. Full instructions for electronic submission are available directly from this site. If you are unsure of the suitability of your manuscript, please e-mail the abstract to the Journal Office before submitting online: ipaj-ed@unimelb.edu.au To facilitate rapid reviewing, communications for peer review will be electronic and authors will need to supply a current e-mail address when registering to use the system.

When submitting your manuscript you will need to supply: A cover letter, the manuscript with the text file in MS Word format, and all figures in TIFF or JPEG format. If the paper reports the results of a randomized controlled trial please ensure that it conforms to our requirements listed below under the heading ‘Submission of randomized clinical trials’ on page 2. If the research was paid for by a funding organization, the cover letter must contain the following three statements (this information does not have to be included in the manuscript itself but only in the cover letter). If the research was not paid for by a funding organization only the third statement is required: 1. That the authors have not entered into an agreement with the funding organization that has limited their ability to complete the research as planned and publish the results. 2. That the authors have had full control of all the primary data. 3. That the authors are willing to allow the journal to review their data if requested.

Submission of a manuscript will be taken to imply that all listed authors have seen the final version and approved it.

All papers will be assessed by two reviewers. If their opinions are too disparate to permit the Editor-in-Chief to make a decision on publication or the reviewers are unable to make clear recommendations, the paper will be assessed by a third reviewer. **The Editor-in-Chief’s decision to accept, reject or request revision of the paper for publication will be final.** The abstract and author details will be seen by prospective reviewers of the manuscript. Authors can suggest the names and contact information of experts qualified to review the work, but the Editor-in-Chief is not obliged to follow these suggestions. Papers must bear the authors’ names, titles (e.g., Dr, Professor, etc.), affiliation(s), and address(es). This information will be seen by reviewers. Reviewers’ names will not be supplied to authors unless a reviewer asks to be so identified. Authors

will be provided with a copyright transfer form to sign after acceptance of the manuscript, consenting to publication of the paper in *International Psychogeriatrics*.

The receipt of all submitted papers will be acknowledged. Authors who do not receive an acknowledgement of receipt of their paper within three weeks of submission should assume that their paper has not been received and should contact ipaj-ed@unimelb.edu.au, Professor Nicola Lautenschlager. Normanby House, St George's Hospital, 283 Cotham Road, Kew, Victoria, 3101, Australia, Tel: +61 3 9816 0485, Fax: + 61 3 9816 0477. Most authors can expect to receive an initial decision on the fate of their paper together with referees' reports within no more than 100 days of submission. Authors who have received no further communication 120 days after acknowledgment of receipt of their article should contact ipaj-ed@unimelb.edu.au.

Reviews of the Literature

International Psychogeriatrics will publish at least 1 literature review in each issue. Authors intending to submit a literature review should check recent issues of *International Psychogeriatrics* to ensure that no review of the topic they propose to discuss has been published in the journal in recent times. Review articles may have up to 50 relevant references. Authors contemplating the submission of a literature review article are welcome to contact the editor to discuss the appropriateness of the topic prior to submission (ipaj-ed@unimelb.edu). Literature reviews should have an abstract.

References

International Psychogeriatrics uses the Harvard referencing system. Within the text of each paper journal articles should be cited in the style (Smith and Jones, 1999). Where an article quoted in the body of the text has more than two authors the term “*et al.*” should be employed, i.e., (Smith *et al.*, 1999). Text citations of multiple articles should be separated by semicolons, i.e., (Smith and Jones, 1999; Smith *et al.*, 1999). At the end of each paper, all cited references should be listed alphabetically in the style indicated below. If the Digital Object Identifier (doi) is known, it should be added to the reference.

For a journal article:

Smith, J., Jones, W. I. and Doe, J. T. (1996). Psychogeriatrics for pleasure and profit: an expanding field. *International Journal of Unreproducible Results*, 3, 240–242.
doi:12.3456/S123456789.

For a book:

Smith, J.A., Brown, P.Q., Jones, H.A. and Robinson, D.V. (2001). *Acute Confusional States*. New York: Cambridge University Press.

For a book chapter:

Park, K., Tiger, B. and Runn, F. (1999). Psychogeriatrics in context. In G. Verdi and A. Boito, (Eds.) *New Medical Specialties* (pp. 240–260) Cambridge: Cambridge University Press.

Where an article or book chapter has more than six authors only the first author's name should be given followed by the words “*et al.*”.

3i	Participant Characteristics	Is there a clear description of the sample? Does it provide adequate details of the sample used in the study, critical to the understanding of findings are described? (sample number, age, sex, dwelling, diagnosis).						
3ii	Methodology	Is there adequate description of the measures used in the collection of data? (e.g. description of questionnaire or interview schedule or a description of interview topics)						
3iii	Data Analysis	Did the report provide an adequate description of the methods used in data analysis?						
4	Method & Results *							
4ai	a. Qualitative	Are the sources of qualitative data (archives, documents, informants, observations) relevant to address the research question (objective)?						
4aii		Is the process for analyzing qualitative data relevant to address the research question (objective)?						
4aiii		Is appropriate consideration given to how findings relate to the context, e.g., the setting, in which the data were collected?						

4aiv		Is appropriate consideration given to how findings relate to researchers' influence, e.g., through their interactions with participants?						
4bi	b. Quantitative randomized controlled (trials)	Is there a clear description of the randomization (or an appropriate sequence generation)?						
4bii		Is there a clear description of the allocation concealment (or blinding when applicable)?						
4biii		Are there complete outcome data?						
4biv		Is there low withdrawal/drop-out?						
4ci	c. Quantitative non-randomized	Are participants (organizations) recruited in a way that minimizes selection bias?						
4cii		Are measurements appropriate (clear origin, or validity known, or standard instrument; and absence of contamination between groups when appropriate) regarding the exposure/intervention and outcomes?						

4ciii		In the groups being compared (exposed vs. non-exposed; with intervention vs. without; cases vs. controls), are the participants comparable, or do researchers take into account (control for) the difference between these groups?						
		Are there complete outcome data (80% or above), and, when applicable, an acceptable response rate (60% or above), or an acceptable follow-up rate for cohort studies (depending on the duration of follow-up)?						
4civ								
4di	d. Quantitative descriptive	Is the sampling strategy relevant to address the quantitative research question (quantitative aspect of the mixed methods question)?						
4dii		Is the sample representative of the population understudy?						
4diii		Are measurements appropriate (clear origin, or validity known, or standard instrument)?						
4div		Is there an acceptable response rate (60% or above)?						

4ei	e. Mixed methods	Is the mixed methods research design relevant to address the qualitative and quantitative research questions (or objectives), or the qualitative and quantitative aspects of the mixed methods question (or objective)?						
4eii		Is the integration of qualitative and quantitative data (or results*) relevant to address the research question (objective)?						
4eiii		Is appropriate consideration given to the limitations associated with this integration, e.g., the divergence of qualitative and quantitative data (or results*) in a triangulation design?						
5	Discussion							
5i	Key Results	Does it summarise key results with reference to study objectives?						
5ii	Limitations	Does it discuss limitations of the study, taking into account sources of potential bias or imprecision? Does it discuss both direction and magnitude of any potential bias?						

5iii	Interpretation	Does it give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence?						
5iv	Generalisability	Does it discuss the generalisability (external validity) of the study results?						
	Totals							
								%

Appendix C – Data Extraction Tool

Study Characteristics

- Title
 - Authors
 - Date
 - Country of Origin
-

Study Aims

- Rationale
 - Hypotheses
-

Participant Characteristics

- Sample size
 - Age
 - Gender
 - Other Socio-demographics
-

Health Condition(s) Investigated

Variables Studied & Measures

Method and Design

Results

Conclusions

Themes

Quality Score

Appendix D: Methodological Quality Assessment

Item	Criteria	Grzywacz et al. (2011)	Grzywacz et al. (2012)	Gump et al (2001)	Hampson & Glasgow (1996)	Hampson et al. (1995)	Hampson et al. (1994)	Lin et al. (2012)	Lin & Heidrich (2012)	Schüz et al. (2012)	Tolmie et al. (2001)	Total	Max Score
Abstract	Clarity and precision	1	1	2	1	2	2	2	2	2	1	16	20
Introduction	Background and rationale	2	2	2	2	2	2	2	2	2	1	19	20
	Key Concepts	2	2	2	2	2	2	2	2	2	1	19	20
	Aims and Objectives (Statement)	2	2	2	2	1	2	2	2	2	2	19	20
	Aims and Objectives (Design)	2	2	2	1	1	2	2	2	2	2	18	20
	Context	2	2	2	0	2	2	2	2	2	2	18	20
Method and result (all designs)	Participant characteristics	1	1	2	2	1	2	2	2	2	2	17	20
	Methodology	1	1	1	1	1	2	2	1	2	1	13	20
	Data Analysis	1	2	2	2	2	2	2	2	2	2	19	20
*Quantitative	Sampling	2	1	2	2	1	2	1	1	2	1	15	20
	Measures	1	1	0	1	2	1	2	2	1	2	13	20
	Representative	1	1	2	1	2	1	2	2	2	2	16	20
	Response rate	0	1	1	1	2	2	2	1	2	0	12	20

Item	Criteria	Grzywacz et al. (2011)	Grzywacz et al. (2012)	Gump et al (2001)	Hampson & Glasgow (1996)	Hampson et al. (1995)	Hampson et al. (1994)	Lin et al. (2012)	Lin & Heidrich (2012)	Schüz et al. (2012)	Tolmie et al. (2001)	Total	Max Score
*Qualitative	Sources	2										2	2
	Analysis	1										1	2
	Context	1										1	2
	Researcher Influence	0										0	2
*Mixed Methods	Design	1										1	2
	Integration	1										1	2
	Limitations	1										1	2
		1										1	2
Discussion	Key Results	2	2	2	2	2	2	2	2	2	2	20	20
	Limitations	2	1	2	2	1	1	1	1	2	2	15	20
	Interpretation	2	2	2	2	2	2	2	2	2	2	20	20
	Generalisability	1	2	2	1	1	2	2	2	2	1	16	20
Percentage		66%	76%	82%	71%	79%	91%	94%	88%	97%	76%		

Appendix E – Submission guidelines for the *Journal of Psychology and Health*

Instructions for authors

This journal uses ScholarOne Manuscripts (previously Manuscript Central) to peer review manuscript submissions. Please read the [guide for ScholarOne authors](#) before making a submission. Complete guidelines for preparing and submitting your manuscript to this journal are provided below.

The instructions below are specifically directed at authors who wish to submit a manuscript to *Psychology & Health*. For general information, please visit the [Author Services](#) section of our website.

***Psychology & Health* considers all manuscripts on the strict condition that they have been submitted only to *Psychology & Health*, that they have not been published already, nor are they under consideration for publication or in press elsewhere. Authors who fail to adhere to this condition will be charged with all costs which *Psychology & Health* incurs and their papers will not be published.**

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Manuscript preparation

1. General guidelines

- Papers are accepted only in English. British spelling and punctuation is preferred. Please use single quotation marks, except where ‘a quotation is “within” a quotation’. A typical article will not exceed 30 pages¹ (inclusive of tables/references/figure captions/footnotes/endnotes), with a font size of 12 in New Times Roman, and all margins should be at least 2.5cm. Papers that greatly exceed this will be critically reviewed with respect to length. Authors should include a word count with their manuscript. Manuscripts should be double-spaced throughout (including tables and references), and each page should be numbered consecutively.
- Manuscripts should be compiled in the following order: title page; abstract; keywords; main text; acknowledgments; appendixes (as appropriate); references; table(s) with caption(s) (on individual pages); figure caption(s) (as a list).
- [Abstracts](#) of no more than 200 words are required for all papers submitted. The primary headings for the structured abstracts will be: Objective, Design, Main Outcome Measures, Results, Conclusion.
- Each paper should have three to six [keywords](#) or phrases . These will be used for indexing and data retrieval, and so where appropriate we recommend using standard MeSH terms (the terms used for indexing articles for MEDLINE).
- Search engine optimization (SEO) is a means of making your article more visible to anyone who might be looking for it. Please consult our guidance [here](#) .
- All the authors of a paper should include their full names, affiliations, postal addresses, telephone numbers and email addresses on the cover page of the manuscript. One author should be identified as the corresponding author. The affiliations of all named co-authors should be the affiliation where the research was conducted. If any of the named co-authors moves affiliation during the peer review process, the new affiliation can be given as a footnote. Please note that no changes to affiliation can be made after the article is accepted.

¹ Please note that the formatting of the Empirical Paper is different to these guidelines. This is due to binding guidelines. If the format of the journal is applied the paper is in line with the page count.

- For all manuscripts non-discriminatory language is mandatory. Sexist or racist terms should not be used.
- Authors must adhere to [SI units](#) . Units are not italicised.
- When using a word which is or is asserted to be a proprietary term or trade mark, authors must use the symbol ® or TM.
- Reports of statistical tests should include an indication of effect size whenever possible. Reports of randomised controlled trials should state any registration details of the trial and should follow CONSORT guidelines where relevant (see Moher, D., Schulz, K.F. & Altman, D.G. for the CONSORT group, 2001. The CONSORT statement: Revised recommendations for improving the quality of reports of parallel-group randomized trials. *Annals of Internal Medicine*, 134, 657-662).

2. Style guidelines

- Description of the Journal's [article style*](#) , [quick guide](#)
- Description of the Journal's [reference style**](#)
- [Guide to using mathematical symbols and equations](#)
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3. Figures

- It is in the author's interest to provide the highest quality figure format possible. **Please be sure that all imported scanned material is scanned at the appropriate resolution: 1200 dpi for line art, 600 dpi for grayscale and 300 dpi for colour.**
- Figures must be saved separate to text. Please do not embed figures in the paper file.
- Files should be saved as one of the following formats: TIFF (tagged image file format), PostScript or EPS (encapsulated PostScript), and should contain all the necessary font information and the source file of the application (e.g. CorelDraw/Mac, CorelDraw/PC).

- All figures must be numbered in the order in which they appear in the paper (e.g. Figure 1, Figure 2). In multi-part figures, each part should be labelled (e.g. Figure 1(a), Figure 1(b)).
- Figure captions must be saved separately, as part of the file containing the complete text of the paper, and numbered correspondingly.
- The filename for a graphic should be descriptive of the graphic, e.g. Figure1, Figure2a.

*Article Style

Running heads	<i>(verso) J. Smith and P. Jones or J. Smith et al. if 3 or more authors. If J.B. Smith then initials are closed up</i> <i>(recto) Journal Title</i> centred on pages
Article type (when needed)	RESEARCH ARTICLE bold caps, centred
Title	Bold, first word and proper nouns cap only centred
Authors	An Author and Another Author (initials closed up if J.B. Smith) centred
Affiliation	<i>^aDepartment, University, City, Country;</i> <i>^bDepartment, University, City, Country</i> centred
Received dates	<i>(Received 20 July 2011; accepted 17 August 2012)</i> After affiliation, centred
Abstract	Text smaller, indented both sides Centred
Keywords	Keywords: word; another word; lower case except names Position aligned with abstract, same size as abstract

Correspondence details	Given as footnote on page 1* *Corresponding author. Email: xxxxxxx ranged left, no indent. Postal address not included in footnote. If there is only one author, use *Email: xxxxxxx
Headings	A. Bold initial cap only B. <i>Bold italic initial cap only</i> C. <i>Italic initial cap only</i> D. <i>Italic initial cap only</i>. Text runs on All ranged left, numbers to be included if supplied, no indent below.
Paragraphs	Indented
Tables	(Table 1) in text. Table 1. Title initial cap only. (ranged left above table) Note: This is a note. (ranged left under table)
Figures	(Figure 1) in text. Figure 1. Caption initial cap only. (ranged left under figure) Note: This is a note. (ranged left under figure)
Permissions statement for third-party figure and table captions	If the rights holder has supplied text for this purpose, use their text. Otherwise, insert the rights holder's name within the square brackets: © [Rights holder]. Reproduced by permission of xxx. Permission to reuse must be obtained from the rights holder.
Displayed quotations	Indented left and right, smaller font (over 40 words, or when appropriate)
Lists	(1) for numbered lists Bullets if wanted

Equations	Equation (1) in text Centred
Acknowledgements	A heading. Goes before notes, bio notes and refs Text smaller
Funding	A heading. Goes after Acknowledgements Text smaller Funding agency written out in full. Grant number in square brackets. Multiple grant numbers separated by comma and space. Agencies separated by semi-colon, e.g. This work was supported by the Wellcome Trust [grant number]. This work was supported by the Wellcome Trust [grant number], [grant number]; Cancer Research UK [grant number]; another

**** Referencing Style**

APA (American Psychological Association) references.

For detailed information, please see the *Publication Manual of the American Psychological Association*, 6th edition, <http://www.apastyle.org/> and <http://blog.apastyle.org/>.

Manuscript submission

All submissions should be made online at the *Psychology & Health* [Scholar One Manuscripts site](#). New users should first create an account. Once logged on to the site, submissions should be made via the Author Centre. Online user guides and access to a helpdesk are available on this website.

Submitted papers will be subject to blind review. Authors should prepare and upload two versions of their manuscript. One should be a complete text, while in the second all information identifying the author should be removed from files to allow them to be

sent anonymously to referees. When uploading files authors should define the non-anonymous version as "File not for review".

Each paper will be read by at least two referees. Authors will be invited to suggest preferred and non-preferred reviewers when they submit the manuscript, but the editors reserve the right to make the final decision regarding choice of reviewers. Authors should not suggest reviewers with any conflict of interest (e.g. reviewers with whom they have recently collaborated, or from their own institution).

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Appendix F – Semi-structured Interview Schedule²

I would like to ask you some questions about your epilepsy. A lot of people with this condition have different opinions and experiences. I am interested to know about **your** experience and beliefs about your epilepsy.

Illness Identity

1. *Can you tell me your story and how you started attending this clinic?*

- What are the reasons that you visit this clinic?
- What made you realise that something was wrong? How/ when did you realise that something was wrong?
- How would you describe epilepsy to other people?

Timeline

2. *How long do you think your epilepsy will last?*

- How do you think your epilepsy will be like in one year's time? What changes do you anticipate?

Consequences

3. *How does epilepsy affect your life?*

- What is the impact of epilepsy in your life?
- How did epilepsy change your life?
- What are the most difficult effects/ consequences of your epilepsy?
- Can you tell me about any good effects/ consequences of your epilepsy?

Control/ Cure

4. *How much control do you feel that you have on your epilepsy?*

- How do you think your epilepsy can be treated?
- What/ who can help you manage/control the epilepsy?

Cause

5. *What do you think is the cause of your epilepsy?*

Other

6. *Is there anything else that you would like to say?*

- Is there anything else that would be helpful for me to know?

Examples of general prompts:

- Can you tell me a bit more about that?
- Earlier you mentioned....tell me more about that.
- How was that for you?
- How did you feel when.....?

² The Interview Schedule was adapted from:

. Green, A., Payne, S., & Barnitt, R. (2004). Illness representations among people with nonepileptic seizures attending a neuropsychiatry clinic: a qualitative study based on the self-regulation model. *Seizure*, 13,331–339.

Nicholls, C. C., Glover, L. L., & Pistrang, N. N. (2004). The illness experiences of women with fibroids: An exploratory qualitative study. *Journal Of Psychosomatic Obstetrics & Gynecology*, 25(3-4), 295-304.

Appendix G – Ethical Approval Documentation

Re-issue of Favourable Opinion Letter. Emma Wolverson's position amended from Chief Investigator to Primary Academic Supervisor. Requested by Haris Yennadiou on 29th May 2012



NRES Committee East Midlands - Nottingham 2

The Old Chapel
Royal Standard Place
Nottingham
NG1 6FS

Telephone: 0115 8839437
Facsimile: 0115 8839294

29 May 2012

Miss Haris Yennadiou
Department of Clinical Psychology
Hertford Building, Hull University
Cottingham Road, Hull
HU6 7RX

Dear Miss Yennadiou

Study title: The experience of epilepsy in older people: an exploration of illness representations
REC reference: 12/EM/0227
Protocol number: N/A

The Proportionate Review Sub-committee of the NRES Committee East Midlands - Nottingham 2 reviewed the above application on 28 May 2012.

- The lead reviewer spoke to you prior to the meeting. The lead reviewer was informed that Dr Emma Wolverson is now the primary academic supervisor for the study after returning from maternity leave.
- The lead reviewer asked you if you are aware of the lone working policy and you informed her that you are.
- The committee agreed that this was a category 5 of proportionate Review

Ethical opinion

On behalf of the Committee, the sub-committee gave a favourable ethical opinion of the above research on the basis described in the application form, protocol and supporting documentation, subject to the conditions specified below.

Ethical review of research sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Re-issue of Favourable Opinion Letter. Emma Wolverson's position amended from Chief Investigator to Primary Academic Supervisor. Requested by Haris Yennadiou on 29th May 2012

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

You should notify the REC in writing once all conditions have been met (except for site approvals from host organisations) and provide copies of any revised documentation with updated version numbers. Confirmation should also be provided to host organisations together with relevant documentation.

Approved documents

The documents reviewed and approved were:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Interview Schedules/Topic Guides	1.1	27 March 2012
Investigator CV	Emma Wolverson	
Investigator CV	Haris Yennadiou	16 May 2012
Other: Peer review		18 November 2011
Participant Consent Form	1.1	27 March 2012
Participant Information Sheet	1.1	27 March 2012
Protocol	1.1	09 December 2011
Questionnaire: Demographic Questionnaire	1.1	27 March 2012
REC application	97801/32675 5/1/664	22 May 2012

Membership of the Proportionate Review Sub-Committee

The members of the Sub-Committee who took part in the review are listed on the attached sheet.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

Re-issue of Favourable Opinion Letter, Emma Wolverson's position amended from Chief Investigator to Primary Academic Supervisor. Requested by Haris Yennadiou on 28th May 2012

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

Feedback

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

Further information is available at National Research Ethics Service website > After Review

12/EM/0227

Please quote this number on all correspondence

With the Committee's best wishes for the success of this project

Yours sincerely



Dr Frances Game
Alternate Vice Chair

Email: stephen.briggs@notts.nhs.uk

Copy to:

Sponsor - Mr Stephen Walker, Humber NHS Foundation Trust

Re-issue of Favourable Opinion Letter. Emma Wolverson's position amended from Chief Investigator to Primary Academic Supervisor. Requested by Haris Yennadiou on 29th May 2012

NRES Committee East Midlands - Nottingham 2

Attendance at PRS Sub-Committee of the REC meeting on 28 May 2012

Committee Members:

<i>Name</i>	<i>Profession</i>	<i>Present</i>	<i>Notes</i>
Dr Frances Game	Consultant Physician	Yes	
Miss Catherine Shenton	Lay Member	Yes	
Miss Alison Thorpe	Research Technician / part time PhD	Yes	
Ms Margret Vince	Translator	Yes	

Also in attendance:

<i>Name</i>	<i>Position (or reason for attending)</i>
Mr Stephen Briggs	Assistant Co-ordinator
Miss Heather Harrison	Committee co-ordinator

York Teaching Hospital **NHS**

NHS Foundation Trust

Research & Development
Learning and Research Centre
York Hospital
Wigginton Road
York YO31 8HE
Direct line: (01904) 726996

R&D Unit reference: YOR-A02118

3rd September 2012

Miss Haris Yennadiou
Department of Clinical Psychology
Hertford Building
Hull University
Cottingham Road
Hull HU6 7RX

Dear Miss Yennadiou

NHS Management Permission to undertake a research study
Trust: York Teaching Hospital NHS Foundation Trust
Study Title: The experience of epilepsy in older people: an exploration of illness representations

Thank you for submitting details of this trial for NHS Management Permission from the above-named Trust

On behalf of the Trust I confirm that Management Permission to conduct the study at this site is granted. The Sponsor should accept this as confirmation that all necessary governance checks have been made. Please note that this NHS Permission is based on the documents included on the attached list. Any subsequent amendments must be notified to the R&D Unit

Yours sincerely



Damon Foster
R&D Manager

cc: Professor Pamela Crawford; R&D Unit Research Monitoring Officer

APPENDIX 2: APPROVED DOCUMENTS

Copy to be enclosed with NHS Permission letter (and, where appropriate, with Participant Recruitment letter)

*R&D Unit: Complete table during NHS Permission application. Copy entries from Checklist for documents marked *. If any revised documents are approved as amendments during the NHS Permission process update this table so it provides a record of key document / versions as at the date of NHS Permission. If any revised documents are approved as amendments between NHS Permission letter and Participant Recruitment letter for an interventional study, update this table and send it out with the latter.*

Document	Version / Date
Protocol	Version 1.1
Participant Information Sheet	Version 1.1
Consent Form	Version 1.1



Health Research Authority

NRES Committee East Midlands - Nottingham 2

The Old Chapel
Royal Standard Place
Nottingham
NG1 6FS

Tel: 0115 8839428
Fax: 0115 9123300

18 January 2013

Miss Haris Yennadiou
Department of Clinical Psychology
Hertford Building, Hull University
Cottingham Road, Hull
HU6 7RX

Dear Miss Yennadiou

Study title: The experience of epilepsy in older people: an exploration of illness representations
REC reference: 12/EM/0227
Amendment number: 1
Amendment date: 19 December 2012
IRAS project ID: 97801

The above amendment was reviewed by the Sub-Committee in correspondence.

Ethical opinion

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

Approved documents

The documents reviewed and approved at the meeting were:

Document	Version	Date
Letter of invitation to participant	1.1	11 December 2012
Protocol	1.2	17 December 2012
Notice of Substantial Amendment (non-CTIMPs)	1	19 December 2012

Membership of the Committee

The members of the Committee who took part in the review are listed on the attached sheet.

R&D approval

All investigators and research collaborators in the NHS should notify the R&D office for the relevant NHS care organisation of this amendment and check whether it affects R&D approval of the research.

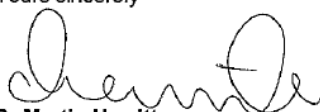
Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

We are pleased to welcome researchers and R & D staff at our NRES committee members' training days – see details at <http://www.hra.nhs.uk/hra-training/>

12/EM/0227:**Please quote this number on all correspondence**

Yours sincerely

pp 

Dr Martin Hewitt
Chair

E-mail: nrescommittee.eastmidlands-nottingham2@nhs.net

Enclosures: *List of names and professions of members who took part in the review*

Copy to: *Care organisation / Sponsor - Mr Stephen Walker, Humber NHS Foundation Trust*

NRES Committee East Midlands - Nottingham 2

Attendance at Sub-Committee of the REC meeting on 18 January 2013

<i>Name</i>	<i>Profession</i>	<i>Capacity</i>
Dr Frances Game	Consultant Physician	Expert
Dr Martin Hewitt	Consultant Paediatric Oncologist	Expert

York Teaching Hospital

NHS Foundation Trust

Research & Development
Learning and Research Centre
York Hospital
Wigginton Road
York YO31 8HE
Direct line: (01904) 726996

R&D Unit reference: YOR-A02118
Eudract Number: N/A

28th January 2013

Miss Haris Yennadiou
Department of Clinical Psychology
Hertford Building, Hull University
Cottingham Road, Hull
HU6 7RX

Dear Miss Yennadiou

Acknowledgement of an amendment to a research study

Trust: York Teaching Hospital NHS Foundation Trust
Study Title: The experience of epilepsy in older people: an exploration of illness representations
Amendment Number: Substantial Amendment 1
Ethics Committee Favourable Opinion dated: 18th January 2013

Thank you for providing details of the above amendment to this trial.

I acknowledge receipt of the amendment and confirm that there is no objection to its implementation in this Trust

Please note that this acknowledgement applies only to those documents granted a favourable ethical opinion on the above date.

I am forwarding copies of the documentation to the Principal Investigator in the Trust

Yours sincerely



Damon Foster
R&D Manager

cc: Professor Pamela Crawford; Andy Gibson; Zoe Coleman

Appendix H – Participant Information Sheet

Participant Information Sheet

We would like to invite you to take part in our research study which is looking at the experience of epilepsy in older people. Before you decide if you want to participate we would like you to understand why this research is being done. We would also like you to understand what it will involve for you if you decide to participate. You can talk to others if you would like before you decide if you want to take part. ***The researcher will answer any questions you may have.***

What is the purpose of the study?

We know very little about what it is like for older people to live with a diagnosis of epilepsy and how it impacts on their life. This study is looking to understand more about how older people experience epilepsy. We are also looking to understand more about people's beliefs about their epilepsy. We hope that this study will help us understand more about these issues which will hopefully help improve support and treatment plans.

Why have I been invited?

This information is given to service-users who attend the clinic, who suffer from epilepsy and are above the age of 65. Staff members at the clinic give this information sheet to people who may fulfil the criteria to take part in the study as they may be interested in participating.

Do I have to take part?

No, participation is completely voluntary. If you decide to take part you will be asked to sign a consent form to indicate that you agree to take part. You are free to withdraw from the study at any point and you do not have to give a reason for this. Your decision will not affect your medical care or your legal rights.

What will happen if I decide to take part?

If you agree to take part please leave your contact details with a member of staff. Then you will be contacted by the researcher to arrange a meeting at a convenient place and time. You will have to answer some short questions about you, for example your gender and your age. Then you will have a conversation with the researcher which will last around 60 minutes. The researcher who is a trainee clinical psychologist will be asking you some more

questions about your experience of epilepsy and will audiotape the discussion. There are no right or wrong answers and we are only interested in your opinions, your beliefs and your experience of epilepsy.

What are the possible disadvantages and risks of taking part?

Participating in the study will require 60 minutes of your time and this may be inconvenient for you. Some people may experience emotional distress when they talk about their experience of epilepsy because it may bring to mind difficult issues about the epilepsy. If this happens to you the researcher will offer support and help you to gain access to further help from your clinical care team or your GP, if needed.

What are the possible benefits of taking part?

We cannot promise that you will have any direct benefits from taking part in the study. However, it is hoped that the information you give us will help us to understand more about epilepsy and about the particular issues of epilepsy in older age. It may also help to improve relevant treatment plans and support from services.

What will happen if I decide I no longer wish to take part?

You are free to withdraw from the study before the results are analysed and the study is written-up without giving a reason. This will not affect your legal rights or the medical care that you receive in the clinic.

What if there is a problem?

If you have a concern about the study you can contact the researcher or their supervisor who will do their best to answer your questions.

Will my taking part in this study be kept confidential?

Yes, all the personal information that you provide will be kept strictly confidential. Any information that could be used to identify you will not be used in the research. The people who will decide to participate will be given a code to protect their anonymity. After the research is completed all the audio recordings will be destroyed. The only time that information cannot be kept confidential is if you disclose something that suggests that you or someone else is at risk of serious harm. If this happens during the interview the researcher will need to contact appropriate authorities to ensure that you and other people are safe. It is unlikely that this will happen and the researcher will try to discuss this with you.

What will happen to the results of the study?

After the study is completed if you wish you will be given written feedback about the results of the study. We will also invite you to make comments on the results if wish but this will be completely voluntary. Then the results will be written-up and submitted for publication in an academic journal. Some direct quotes from your interview may be used in the write-up. Your personal details and any identifiable data **will not** be included in the write-up.

Who is organising and funding the research?

This research is being undertaken as part of a doctoral research project in Clinical Psychology. The research is funded and regulated through the University of Hull. Some relevant sections of data collected during the study which are relevant to taking part in this research may be looked at by responsible individuals from the University of Hull or from regulatory authorities to ensure that appropriate guidance was followed by the researcher.

Who has reviewed the study?

The study is reviewed by an independent organisation which is called the Research Ethics Committee. The Research Ethics Committee protects the interest of people who participate in research. This study has been reviewed by the East Midlands Nottingham Research Ethics Proportionate Review Sub-Committee and has received a favourable opinion.

If you have any further questions, comments or queries, please don't hesitate to contact Haris Yennadiou. Thank you for taking the time to read this information.

Yours Sincerely,

Haris Yennadiou
Trainee Clinical Psychologist

Supervised by,

Dr Emma Wolverson
Clinical Psychologist

Further information and contact details

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If you are interested to take part in the study please leave your contact details on the space provided below. You will be contacted by the researcher to arrange a meeting at a convenient place and time.

Name:

.....

Address:

.....

.....

.....

.....

Telephone Number:

.....

Mobile Phone Number:

.....

Are there any times of the day that you prefer to be contacted?

.....

Do you have any further comments?

.....

.....

Signature:.....

Date:.....

Thank you very much for your interest!

Appendix I – Participant Consent Form

Participant Identification Number:

CONSENT FORM

Please put your initials in the boxes to indicate your agreement:

1. I confirm that I have read and understand the information dated on the 27 th of March 2012 for the above study. I had the time to consider all the information, ask questions and received satisfactory answers.	☐
2. I understand that my participation is not compulsory and that I have the right to withdraw from the study at any point before the analysis and write-up of the study without giving a reason. If I withdraw from the study my legal rights and medical care will not be affected in any way.	☐
3. I understand that the researcher will conduct an interview with me and audio-record it.	☐
4. I understand that relevant sections of data collected during the study may be looked at by responsible individuals from the University of Hull or from regulatory authorities, where it is relevant to taking part in this research.	☐
5. I agree to take part in the above study	☐
6. I agree to allow the named researcher to contact me using the contact details I provide to inform me about the results of this study.	☐

Name of Participant

Signature

Date

.....

Researcher

Signature

Date

.....

Appendix J: Demographic Questions

I would like to start by asking you some questions about you and some questions about your epilepsy. Please try to answer these questions as accurately as you can but don't worry if you are not sure about your answer.

1. What is your age in years?

.....

2. What is your gender? Please circle the one that applies to you.

Male/ Female

3. What is your ethnic background? Please circle the one that applies to you.

- White British
- Other White background (please specify).....
- Multiple Ethnic background (please specify).....
- Asian
- Asian British
- African / Caribbean
- African British/ Caribbean British
- Other Ethnic Group (please specify).....

4. How old were you when you were diagnosed with epilepsy?

.....

5. What type of epilepsy were you diagnosed with?

.....

6. When was the last time you experienced a seizure?

.....

7. What medications do you take for your epilepsy?

.....

Do you have any other illnesses?

.....

Thank you very much for taking the time to answer these questions!

Appendix K – Epistemology Statement

Epistemology Statement

The aim of this statement is to explore the epistemological and ontological assumptions underpinning the choice of methodology and design employed to address the study's research questions. In the early stages of this research, it was identified that there is very limited existing literature exploring the psychosocial functioning of older people with epilepsy and thus very little scope to build on existing theories and empirical findings. There was also a concern as to whether existing quantitative measures would be able to capture the issues that older people with epilepsy experience (Baker & Jakoby, 2000). Therefore the authors developed the research objectives on a stance of curiosity where the main question was concerned with 'what it might be like to live with epilepsy in later life'. Based on this question a positivist stance usually represented by quantitative research was rejected (Willing, 2001). Positivism suggests that there is a true reality about phenomena in the world that can be measured to achieve objective knowledge (Willing, 2001).

In contrast, constructivist approaches like social constructionism reject the concept of a 'true reality' (Burr, 1995). Instead, such approaches suggest that reality is an idiosyncratic concept that is socially constructed through culture, relationships and particularly the use of language that influence the way an individual perceives the world (Burr, 1995). Approaches like social constructionism hold a relativist stance which values the diversity in individual experiences and the existence of many 'realities' and voices surrounding phenomena (Ponterotto, 2005; Morrow, 2007). Qualitative research aims to understand rather than explain 'cause and effect' relationships between

phenomena (Murrey & Chamberlain, 1999) and such approaches have an important role in clinical and health psychology (Smith, 2008). In health psychology, views on illness and wellbeing have moved from the traditional reductionist biomedical approaches where they were seen as entities (Murrey & Chamberlain, 1999). Instead health and illness are conceptualised as experiences that are constructed, shaped and reflected upon as a person interacts with the world (Murrey & Chamberlain, 1999).

The current study aimed to explore and understand the experience of epilepsy in older people, thus a qualitative approach was chosen. Four different qualitative methods were considered namely; thematic analysis, discourse analysis, grounded theory and interpretative phenomenological analysis (IPA). After careful consideration of the four approaches it was concluded that IPA was the most appropriate methodology to address the research questions. The methodologies considered are explored below:

Thematic Analysis

Thematic analysis is based on an objectivist stance and aims to categorise and describe qualitative data (Anderson, 2007). This approach is therefore concerned with the common features of the voices across participants rather than the individual experience. Interpretation has a minimal role in the analysis of data which may limit the in-depth understanding of phenomena. This method was therefore rejected as this study aimed to understand rather than describe the experience of epilepsy in older people.

Discourse Analysis

Discourse analysis aims to explore and analyse the use of language in sociocultural contexts to describe experiences (Willig, 2001). However the current study aimed to explore the lived experience itself rather than how it is described through

language alone. It also aimed to reach a deeper level of interpretation from what discourse analysis would allow. Thus this approach was also rejected.

Grounded Theory

The main objective of grounded theory is to generate new theory or refine existing theory (Strauss & Corbin, 1994). This approach draws theoretical ideas from qualitative data which are analysed until the point of data saturation (Willig, 2001). Grounded theory was considered unsuitable to address the research question as the aim was not to generate new theory but to explore the ‘lived experience’ of the condition. Furthermore the limited research in the area meant that there were very limited opportunities to draw upon and build on existing theoretical frameworks, thus an initial exploration of the experience was deemed more appropriate.

IPA

IPA was the most appropriate methodology to explore the ‘lived experience’ of epilepsy for older people as this approach aims to examine the process in which individuals make sense of their experiences (Smith, Flowers & Larkin, 2009). Within IPA experience is regarded as an interactive process where the individual interprets their experiences in an attempt to understand them. There are three key theoretical foundations of IPA; phenomenology, hermeneutics and idiography. Phenomenology refers to the study of the individual’s experience i.e. epilepsy which is a process that is unique to the person and their existence in the world. Hermeneutics refer to theory and processes of interpretation of the phenomenology. IPA involves double hermeneutics as the researcher is trying to make sense of how, in this case older people make sense of their experience of epilepsy (Smith, Flowers & Larkin, 2009). Finally, idiography refers

to the interest in the particular where the aim is to understand in detail the specifics of an experience.

Interestingly, IPA has been extensively used in health psychology as it provides a useful approach for exploring the idiosyncratic experience of illness which moves away from historical biomedical understandings (Brocki & Wearden, 2006). Health psychology has recognised the importance of how people understand and interpret their health conditions through their symptoms and the meaning they assign to them (Leventhal et al., 1984). Leventhal's model of illness representations (Leventhal et al., 1984) that was used to design the interview schedule used in this study and is consistent with the ideology of IPA in health psychology as it supports the importance of sense making of illness. The model provided a useful framework for structuring the interview process but was not used for data analysis as the aim of IPA is to prioritise the voice of the individual rather than build on existing research (Smith et al., 2009).

During the process of IPA the researcher is trying to access the individual's personal world (Smith et al., 2009). However, IPA recognises that that it is impossible for the researcher to access complete idiosyncratic experiences of the individual and instead it can only access a partial representation of that personal world (Smith et al., 2009). Given the double hermeneutics the researchers own assumptions, conceptions, experiences and values can complicate and influence the process of interpretation of the participants' experience (Smith & Osborn, 2003). These issues can be addressed to a certain extent if the researcher reflects on their own assumptions and seeks the opinions of others in an attempt to ensure validity (Morrow, 2007). Examples of validation methods may include IPA groups and research supervision.

In light of the above, IPA was decided to be the most suitable methodology to explore the experience and sense making of epilepsy in older people as this approach is concerned with the individual experience. It is that individual experience of epilepsy that the authors' aimed to explore.

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Appendix L: Example of Data Analysis

Ella, Lines 9-46

Emergent Themes

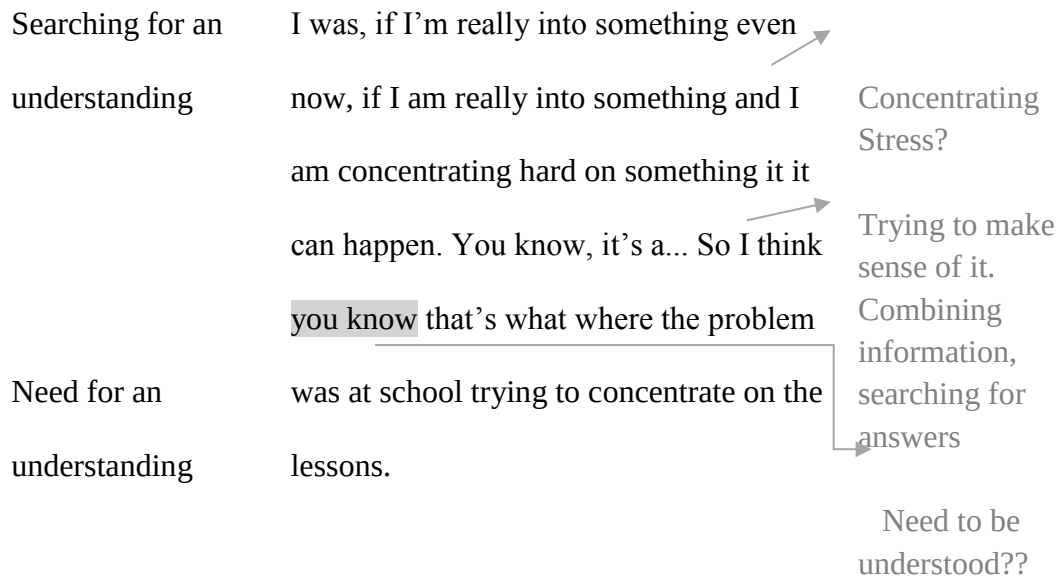
Exploratory

Comments

R - So can you tell me your story and how you started seeing (Epilepsy Nurse) and how you started..., when you realised that things were going wrong or something was wrong?

Not part of the group/ Exclusion	E - When I first realised it, I suppose my first realisation that anything was different to me than the rest of the girls	Being different/ feeling different
Unpredictability	was at school; when I would suddenly drop onto the floor and when I came round everything could alter, you know.	Sudden and unexpected attack
Disconnection	Things like that would be the first time I noticed of it. Eeee, then, the next, as I say when I came back off off honeymoon and	Absent not there - Almost like not being part of her environment – not in control
Takes over	(Husband's name: 'Rob') couldn't get me round and then, that is when I first started to find out that it really was epilepsy.	Again absent – trying to bring her back to the world
Disconnected	Before then it was teenage years and all sorts of things, you know. I think they thought I were fainting. They didn't, the	Different explanations no clear answers
Searching for an understanding	school teachers didn't realise that there was anything different to fainting or	Perhaps being dismissed
Lack of understanding		Lack of knowledge and understanding from others – Folk

	collapsing and gradually coming round.	beliefs
Loss of control	And then after after err I had the bad one when I couldn't come back, I used to thrush about and err and I would come	Not in control of own body
Risk	round and when I came round, I sometimes found that I stopped breathing	Threatening / Danger to own life
Horror	for a few seconds , I would come round with a scream. Well, thankfully, with this	Terrifying experience
Treatment control	medication I don't do that now. I just, I have absolutely no idea that anything has	Importance of medication - treatment
Disconnected	happened. And people would say to me you know you had a fit. No, because I	Absent
Loss of control	absolutely have no idea. I didn't yesterday and it was just, emm so I should I should say, if you want to know	Not Knowing what happens to her, not in control Unaware what others witness
Searching for an understanding	when I first recognised it, it would be at school.	Childhood Experiences and messages about the meaning of epilepsy embedded in life story
	<i>R – Can you tell me a bit more about that?</i>	
'Social' experience	E – Well it used to happen especially in when we was crowded places like in the school hall, if there was a meeting in the school hall or the assembly and that, it did happen a lot. Emmm, other times is if	Public Experience



Example of Supporting Quotes for super-ordinate and subordinate themes

Super-ordinate Themes	Subordinate Themes	Examples of Supporting Quotes ³
The Power of Epilepsy	‘It’s terrible...it’s awful’	<i>‘I’ve had a burn from the old one, I’ve hurt me knees, err things like just general things. Bruises like a lot of other people would with any fall you know and broke me glasses once, as I went down me face broke me glasses.’ (Ella)</i>
		<i>‘But I obviously went down and when I came round I couldn’t move. I’ve bang the coxy of my spine and I was two years having that put right...’ (Ella)</i>
		<i>‘And last September I did that, went over backwards, blacked out and I caught my back of my head, there (Pause) on the pavement stone.... ...and I ended up with a cracked vertebra and a fractured skull.’ (Christine)</i>

³ These quotes are only some of the accounts supporting the themes

'..they rung for an ambulance and I had some really bad ones and my heart stopped two or three times on the way to (Hospital).' (Alfred)

'That was terrible, yeah. I think I had two heart attacks on the way.' (Alfred)

'....the first time I hadn't felt well, so went and made myself a cup of coffee and carried it through, laid down on the settee, and that's when I had the fit and spilled boiling hot coffee all over me' (Carol)

'....third, third degree burns. I was in hospital a long time then. And the second time I had to have skin grafts err I was, I think I just knocked it over onto myself' (Carol)

'I went down into (City) on the road, main road into (City). I got into (City and quite unexpectedly I crashed my car.....' (Ian)

'It was awful for my wife and for my son and my daughter'
(Alfred)

'Well, well.... It was a shock not just for me but it was shock to the family' (Ian)

'But emm I was needing so much treatment and they put me in the side room, I think people having fits are disturbing to other people in the main ward' (Carol)

'Most of them coped with it, but there was one little boy who was quite disturbed, went and hid under the sink in the side room, he couldn't face seeing mommy ill' (Carol)

'I'm quite convinced that one thing it shouldn't happen when you're taking a group around whatever, they don't want this to happen in front of them. That would be the worst experience they could have I would've thought, one of the

worst experiences they could have' (Alan)

'....he had to sit on this boy to keep him sat still, so he wouldn't throw around anymore' (Sarah)

'There was another person, he would be in his 30's now and I've seen him have fits, once or twice so, yeah when I think it happened to me that, it's, it's awful' (Alfred)

'I couldn't I couldn't walk really. I was in a bed state. I asked someone to take me to the bathroom. And of course they were too busy (said in a lower volume), so I finished up on floors, looking for a bathroom.' (Susan)

'I, I wouldn't make it if I if I was put in a hospital again.'
(Susan)

'....you would find that the medical staff on a ward, you would get taken into a ward, you were in a bed. They would simply say to you "Ohhh put him over there, let him sleep it off, he's

only had a seizure". ' (Ian)

'It's an ever present thing is the
epilepsy'

*'I can't see it ending. I am just aware of it and I can't see it
ending. So, it's under control largely but I can't see me ever
saying "no, it won't happen again". I could never say that'
(Beth)*

*'Yes, I haven't had any seizures since I took err these tablets
that were recommended but it is there in the background'
(Beth)*

*'You can't just say I'll ignore it, it's always there, it is always
there' (Alfred)*

*'...from how I understand it no way will I be off this ever....
Until I'm not here anymore you know' (Jenifer)*

*'And this is talking err after starting at 50, now at 70 we've
got 30 years in between so I can't see it ever disappearing*

until the day I die' (Ian)

'But, it is an ever present thing, is the epilepsy.' (Christine)

'...I'm assuming that if that is the case then, that must be the end of the epilepsy. So it will perhaps go away, errr for myself I suspect it won't' (Alan)

'I, I imagine is going to be with me forever after (laughs nervously). It's not something you cure. You have to accept it' (Susan)

'I mean we don't change medication anymore, when I go to see (epilepsy nurse) in (city) I just tell how I'm getting on and everything and she says "well I don't think it's worth changing anything"' (Sarah)

'...well I've been told there is no cure. So it's just a case of keeping it under control as they can' (Ella)

'As they haven't been able to control it with drugs until now, for 30 years, I don't see that they're going to find any drugs or any level of drugs that are going to cure it completely. So I am expecting it to last for the rest of my life' (Carol)

'It was certainly last time as I, I register it as being quick, far quicker than anything that had happened to me before.'
(Alan)

'if anything a little bit strenuous can bring it on' (Jenifer)

'As I say it just came on' (Sarah)

Appendix M - Reflective Statement

During my research journey I have had a wealth of rewarding experiences. In this statement I will outline the key stages of the process and share my reflections, thoughts, emotions and challenges that I have come across along the way, before concluding with some final reflections on what I have learned from this process and my thoughts about the future.

Developing the Study

Choosing the research area

Choosing a research topic was the first important step. I wanted to decide on an area that was within my clinical and research interests. I always believe in making decisions following careful consideration and I wanted my thesis to be a piece of research that was beyond a course requirement for getting a Doctorate Degree in Clinical Psychology. Therefore, in the first stages of exploring a focus area I dedicated time to explore different possibilities for a topic. I mainly concentrated on the psychosocial aspects of physical and neurological conditions as these areas greatly appeal to me. I am fascinated with approaches that see beyond the physiology of illness and neurological conditions so it quickly became apparent that my thesis would concentrate within this field. One of the members of the department brought to my attention the lack of research concerning the psychosocial aspects of epilepsy in later life. I decided to explore the relevant literature and I was surprised by how limited the research was, so I came to the conclusion that this topic would be a fascinating area to explore.

Choosing the Design

After deciding on the topic I began to think about the appropriate design that would bring my ideas to life. With the help of my supervisor I came to the conclusion that an exploratory qualitative study would be the most appropriate approach, given the lack of existing research in the area. I was interested in how people experience epilepsy in later life so IPA seemed to be the most suitable methodology. I was initially a bit apprehensive about conducting a qualitative study. My past experiences and preference in research often took a quantitative approach, therefore choosing a qualitative design was out of my comfort zone. However, as the research idea developed, my interest and curiosity in IPA grew and I was pleasantly surprised to discover the wealth of IPA research in health psychology. The ideology of IPA also appealed to me as it is consistent with a person-centred approach and allows the individual's experiences to be heard. I always value these elements in my clinical practice so I soon began to feel comfortable about my choice of methodology.

Recruitment

Participant recruitment was an anxiety-provoking step along the way. Even though I was aware that IPA does not have a prescriptive participant sample and it usually employs a small number of participants, a part of me was still concerned about the 'right sample size'. Perhaps this was a reflection of my past experiences of quantitative research where the 'right number' of participants is important. During recruitment I managed to build good relationships with professionals in the Neurosciences Department who helped me recruit my first participant. I was so excited to conduct my first interview! Two more interviews followed relatively quickly. However following the first three interviews there was a period where recruitment seemed to stop and I began feeling very anxious. I started thinking about alternative

ways of recruitment, contacted professionals at the Neurosciences Department and approached different services and organisations. This process was time-consuming and stressful. After careful consideration with my supervisor and the Epilepsy Nurses at the Neuroscience Department we decided to approach participants through written invitations that would be sent by the Epilepsy Nurses. I soon discovered that more people wanted to take part which was a great relief!

Interviews

Throughout the interview process I began to realise the true beauty value of IPA. I felt so privileged to conduct research and at the same be trusted with some really inspiring stories. At times hearing some of the experiences was challenging because many participants had experienced some horrific circumstances. It was particularly difficult for me hearing the stigma and discrimination encountered as I never expected that it still exists to this level. I also felt restrained as a clinician because I could not intervene clinically as my role was that of a researcher rather than a trainee clinical psychologist. However there were occasions where participants expressed that they found it helpful talking about their epilepsy and at times I wondered whether qualitative interviews may even facilitate therapeutic processes.

Often partners joined in the interviews to share their views and their part of the story. Initially this created some anxiety for me as I wasn't sure how that would impact on the research. When I reflected on this in supervision I began to realise that perhaps the experience of epilepsy in older people may not reside within the individual alone but it may be a shared experience.

Data Analysis and Write-Up

Data analysis was a dynamic and lengthy process where I was constantly switching from feeling lost in the data, to feeling thrilled because I was discovering fascinating themes and patterns. Every time I read back over the participant's accounts I found myself experiencing so many emotions. Some accounts brought tears to my eyes, particularly the descriptions of the horrific experiences that the participants had to go through. Others made me smile. I was astonished with the resilience, the strong relationships and the wonderful use of humour of the participants. Supervision and the support from the IPA group helped me maintain focus and validate my findings but also reflect on the emotions involved in the process.

One of the most difficult challenges of writing my thesis was choosing the quotes that would represent the themes in the empirical paper. There were so many rich and amazing accounts. I wanted all the participants to be 'heard' within the themes and just choosing a few accounts felt unfair. Again, it was through reflection and the use of supervision that I started thinking about this issue differently. Even if some of the accounts were not included in the write-up they still formed the basis and the evidence for the findings. The accounts were not lost; instead they were embedded in the foundations of each theme.

Systematic Literature Review

The systematic literature review was without a doubt a very challenging piece of work. When I decided on the topic I assumed that there would be a lot of research in the area and I was looking forward to reviewing the literature. Initially, I was disappointed with the sparse and varied research and I doubted my decision to look into this topic. It

was thanks to my supervisor that I regained my enthusiasm as she kept reminding me that it was an interesting and clinically relevant area. Synthesising the data was really difficult and I think I underestimated the time I needed to complete the review. As the process unfolded I started feeling more confident and looking back I am glad that I did not give up on the topic because it enriched my knowledge and highlighted some important areas in clinical health psychology for older people.

Looking back on what I learned and thinking about the future

Reaching the end of this journey makes me feel very lucky that I had the opportunity to learn so much along the way. I have enjoyed research in the past and I have always felt that doing research is a key part of Clinical Psychology. Favouring quantitative approaches in the past, I never imagined that I will come to discover a qualitative approach that I would fall in love with! I am really thankful that I had the opportunity to discover IPA and I would definitely consider this approach in the future. As an approach it values the individual's experience and allows people's voices to be heard. I think that it complements quantitative research and is an invaluable jewel in the world of Clinical and Health Psychology. As one of the participants described, *'personal experience is the best way to learn'* (Ella) and what a wonderful way to learn!

I think there are a number of things that I could do differently from a methodological perspective, some of which I outline in the limitations sections of the two papers. There is always something to improve in research studies, so I will not repeat the methodological flaws of my research. However, there are two things that I would approach differently that I would really like to mention and reflect upon. The first thing I would change is my anxiety for participant recruitment. Looking back I think it was understandable to worry about this difficult process but now I realise that a

larger participant sample does not necessarily add to the quality of IPA. In fact, I think as a novel IPA researcher a smaller participant sample would have felt more manageable and appropriate. Also I regret not considering interviewing couples instead of individuals. As I went through my training I started thinking about people existing in systems and these ideas were reinforced in this study. The experience of illness does not only affect the individual but the people around them. It seems like within relationships people found the strength to cope with really difficult circumstances and I would like to emphasise that and keep it in mind for future research and clinical practice. Along similar lines I always believed that the impact society has on our existence might often be overlooked and my beliefs were supported through the participants' stories of stigma and discrimination.

My final thoughts about my thesis reside within a sense of an ending. I always find it difficult to think about endings, perhaps because they come with so many emotions. Sensing the ending of this piece of work feels like saying goodbye to a part of me. However reflecting on these initial thoughts I actually think that reaching the end marks so many new beginnings. For me, this is a beginning of thinking more about what it might be like to live with epilepsy in later life. It has also been the beginning of my interest in IPA which I am confident that I will consider in the future, both as a clinician and as a researcher. Finally, it hopefully marks the beginning of my career as a future clinical psychologist.