



The experience of epilepsy in later life: A qualitative exploration of illness representations

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ABSTRACT

The objective of this study was to explore how older people living with epilepsy appraise their condition through their lived-experience. The common-sense model of illness representations (CSMIR) provides a framework to explain how individuals make sense of and manage health threats. Semi-structured in-depth interviews based on the CSMIR were conducted with ten people with epilepsy who were above the age of 65. The results were analyzed using Interpretative Phenomenological Analysis. Three overarching themes emerged from the analysis: *'the power of epilepsy'*, *'they say you can live a normal life but you can't'* and *'attempts to adjust and cope'*. Epilepsy was described as a threatening, persistent, and unpredictable condition associated with distressing experiences. Participants described a process of balancing negative psychosocial consequences including stigma, loss of control, and reliance on other people and medication with parallel co-existing coping strategies. These attempts to manage the condition were characterized by a desire for acceptance and increased awareness of epilepsy, strategies to restore loss of control, and strength derived from supportive relationships. We conclude that there is large scope for psychosocial interventions in healthcare provision for this patient group. The roles of specialist nursing, relationship-centered models, psychotherapy, educational, and self-management programs are highlighted.

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1. Introduction

The prevalence of epilepsy in people above the age of 60 is higher than the general population, with incidence rising with increasing age [1]. Epilepsy in older age is associated with increased mortality and difficulties with diagnosis due to atypical symptoms that can mimic other conditions such as dementia [2,3]. Treatment can be complex for older people due to greater risk of antiepileptic medication side effects, physical health changes associated with normal aging and an increased likelihood of medication interactions from the high prevalence of polypharmacy and co-morbidity in later life [4].

Despite these implications and in contrast to extensive literature looking at aspects of quality of life of working age adults with epilepsy [5], the psychosocial functioning of older people with the condition has received little attention. The available literature suggests that the psychological well-being of older people with epilepsy is poorer than the general population [6–8]. Notably, older people with epilepsy display significantly higher levels of depressive symptoms, higher levels of anxiety, more impaired sleep, and lower cognitive status than age-matched controls [9,10].

Little is known about specific issues associated with the experience of epilepsy in later life and the impact on the individual's well-being. Seizures in older age may have different implications and consequences than in earlier stages of life [11]. In addition to coping with epilepsy, older people are likely to face several other challenges and life transitions including retirement, bereavements, loss of role functioning, and co-morbid physical health conditions. Studies to date revealed that older people living with epilepsy are affected by stigma, which leads to nondisclosure of their diagnosis and difficulties in accepting their condition [12].

The evidence as to whether older people have a more impaired quality of life than younger adults with epilepsy is equivocal [6,8]. Interestingly, Pugh and colleagues report a more favorable health status profile for older people compared to middle-aged adults with epilepsy [13], suggesting that older people may be more resilient and have fewer social demands placed upon them. There is some evidence to suggest that there is similarity between the concerns of older people and working age adults with epilepsy, with driving and medication side effects being reported as the most significant concerns [14]. However, older people report more antiepileptic medication side effects which impact on quality of life [6].

The above findings are confounded by limited research in the field, methodological limitations including small samples [8,9], and the absence of control groups in some studies [10]. Notably, the measures employed to assess quality of life are developed and validated for the

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general epilepsy population and therefore may not be sensitive to the issues and concerns of older people [11]. To our knowledge, only two qualitative studies have explored psychosocial aspects of epilepsy in older people [12,14], with one of the studies conducted employing structured analysis which arguably restricted the exploratory nature of the enquiry [14].

Qualitative research in epilepsy is increasingly recognized as integral for a more in-depth understanding of peoples' experiences of epilepsy [15]. One framework that can provide further insight into how older people appraise these experiences is the common-sense model of illness representations (CSMIR) [16,17]. The CSMIR proposes that people form illness representations from a range of sources including existing health and illness beliefs, as well as their own experiences, to make sense of health challenges. Illness representations are constructed in five domains: illness identity or beliefs about the symptoms, time line, consequences, causes, and controllability or cure [17]. These illness constructs appear to influence a wide range of health and psychological outcomes including coping, well-being, and treatment adherence [18,19]. Work investigating the illness representations held by working age adults with epilepsy suggests that more negative illness representations and strong illness identity is associated with negative coping, poor adjustment, and higher levels of anxiety [20,21].

The present qualitative study employed Interpretative Phenomenological Analysis (IPA) and aimed to explore the lived experience of epilepsy in later life through older peoples' appraisals of their condition. The IPA methodology provides a rich qualitative analysis and is widely used to understand and interpret how people make sense of illness experience through the use of language [22,23].

2. Methods

2.1. Participants

Ten patients were recruited from a Neurosciences Department in the North of England with 34% respondent rate. This was deemed as an appropriate sample size based on the idiographic nature of IPA and guidance on its methodology [22]. Demographic characteristics and pseudonyms of the participants can be found in Table 1. Participants were White British/English and above 65 years of age as this was the cut-off age for older adult health services in the UK at the time this study was conducted.

All participants had a confirmed diagnosis of epilepsy with a mean average of 23 years since diagnosis (range 2–48 years). For this exploratory study, no exclusion criteria were set in regard to age of epilepsy onset as the study was looking into the lived experience of epilepsy in later life rather than the differences between age of onset per se. Patients were excluded if they had a diagnosis of dementia, a learning disability, a serious co-existing terminal physical condition or a significant mental health condition that could influence their ability to share their experiences of epilepsy. Most participants 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 were taking at least one antiepileptic medication (range 1–3) and nine reported at least one co-existing health condition (range 1–5). Eight lived with their partner and two lived alone.

2.2. Procedure

Patients who met inclusion criteria were identified by two specialist epilepsy nurses who provided an information sheet about the study. Those who contacted the researcher expressing a desire to participate were given a convenient meeting time and location. A brief demographic questionnaire was completed; followed by the semi-structured in-depth interview lasting on average 57 min (range 38–79).

The interview schedule included open-ended questions guided by the components of the CSMIR [16,17]. This model was employed as it attempts to explain how individuals form beliefs and appraisals of a health challenge based on their experiences of that condition. The interview schedule also included a general question pursuing any other issues that participants felt were important (Appendix A). The interview questions were piloted and adapted following consultation with two epilepsy specialist nurses and two older people with epilepsy. The questions served as a guiding framework and did not restrict the exploration of themes to the constructs of the model. Instead, the interview was led by participants' narratives focusing on their priorities when describing their experiences.

2.3. Analysis

The interviews were digitally recorded, transcribed verbatim and analysed using the stages of IPA described by Smith and colleagues [22]. In particular, IPA was chosen as it endeavors to investigate how a person makes sense of a phenomenon under investigation through a close exploration of their 'lived experience' [22]. The process of this analysis requires the application on 'double hermeneutics' where the researcher attempts to interpret how the participant makes sense of their experience [22,24]. The main analysis was conducted by a female trainee clinical psychologist in her mid-twenties who had no personal experience of living with a long-term health condition.

In the initial stages, the researcher was 'immersed' in the data by carefully reading and re-reading each transcript. During this process the researcher noted thoughts, comments, and reflections that appeared significant in the margins of each transcript. The initial notes were then examined for connections that lead to emergent subordinate themes based on psychological concepts and resonant issues. The subordinate themes were structured in a table with illustrative quotes. Subsequently, meaningful connections and patterns between emergent themes were identified. Related themes were clustered together and were provided with an interpretative label leading to the development of superordinate, overarching themes. The process was repeated for each transcript with an emphasis on the idiographic nature of the analysis. A master table was then constructed capturing recurrent and salient subordinate and superordinate themes across participants. The process involved a constant review of the different analytic stages to ensure that the themes were grounded in the accounts.

This study employed the elements of an existing structural model to guide the development of the interview questions. However, the model was not used to guide the analysis. Themes were identified through an analytic process that maintained an exploratory nature and focused on how participants appraised their condition through their own lived experience, as defined by IPA methodology. Other studies employing structural models in IPA research have adopted a similar approach [25,26].

2.4. Quality and validity

While there is no agreed method to ensure validity and quality of qualitative research [22], the second author (E.W.) followed an identical

Table 1
Participants' demographic information.

Participant pseudonym	Age (Mean: 71.8, SD 4.24)	Gender
Beth	73	Female
Ella	69	Female
Alfred	81	Male
Jennifer	72	Female
Ian	70	Male
Christine	73	Female
Carol	68	Female
Sarah	67	Female
Susan	69	Female
Alan	76	Male

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