Written accounts of living with epilepsy: A thematic analysis

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ABSTRACT

This study examines the subjective experience of living with epilepsy by thematically analyzing participants' written accounts of their condition. Writing is seen as an individual act allowing for private exploration, reflection and expression of thoughts and feelings. Participants (n = 20) were recruited from a United Kingdom hospital and from membership-led organizations for individuals living with seizures. Participants were asked to produce four pieces of writing: 1) about their thoughts and feelings about their condition; 2) a letter to their condition; 3) a letter to their younger self; and 4) about a personal value. All writings were analyzed thematically using a theory- and data-driven approach. Five main-themes and 22 sub-themes emerged from the data. Theme 1: 'seizure onset' demonstrated that the development of seizures and subsequent diagnosis was an important event that could change an individuals' identity. Theme 2: 'seizure symptoms' revealed participants externalized their seizures as an intrusive agent with a constant presence in their lives. Theme 3: 'treatment and outcome' reflected medication as an essential means to controlling seizures with subsequent side effects being perceived as a compromise. Theme 4: 'living with epilepsy' explored the consequences of the condition including restrictions and stigma. Theme 5: 'displays of coping' demonstrated that, for the most part, participants were keen to present themselves as living well with epilepsy. The results add to the growing research applying qualitative methodologies to investigate the phenomenology of epilepsy. Qualitative research can improve our understanding and awareness of the condition, as well as inform clinical practice.

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1. Introduction

Epilepsy is a disorder of the brain characterized by paroxysmal episodes of impaired self-control, associated with a range of motor, sensory and mental manifestations [1]. Living with epilepsy has a multifaceted impact on an individual's life causing emotional, psychological, physical, social and (potentially) financial difficulties [2]. Compared to healthy controls, individuals with epilepsy tend to report lower health-related quality of life (HRQoL), which is predicted by a range of demographic, clinical and psychological factors [3].

In a recent review, Rapport et al. [4] suggests that qualitative research has much to contribute to our understanding of living with epilepsy. Qualitative approaches capture and examine individuals' own words, producing fine-grained insights that are rich in detail. These methodologies enable participants to prioritize and clarify their

experiences, rather than having to choose from limited sets of pre-defined answers — an approach which may oversimplify how the condition affects individual patients. Investigating experiences from a particular individual's perspective taps directly into the problems that are most pressing to those who live with the condition. Such findings can be used to improve our understanding of epilepsy, as well as the quality and outcome of healthcare provisions.

To date, the majority of qualitative research investigating the phenomenology of epilepsy has utilized research interviews [2]. The analysis of different modes of communication such as poetry [5] and drawing [6,7] has also been used. The use of a range of different approaches to collect datasets yields a number of benefits. For example, drawing or writing will provide individuals with a greater opportunity for reflection and more control over the content. Indeed, writing has already been used as an early effort to understand what patients with epilepsy experience in their own words [8]. While such approaches could increase the effects of bias (such as social desirability), spoken responses may not always reflect people's final views. Therefore, a combination of methods based on immediate and more considered thoughts is likely to produce the best possible insights into a problem. Furthermore, participants' responses may be strongly affected by the interview setting, gender and status of the interviewer, the relationship between interviewer and

interviewee, and mode of questioning. These factors may all have a strong influence on the responses of the interviewee [9].

The purpose of the current study was to add to our understanding of life experiences of individuals with epilepsy by thematically analyzing written accounts of their condition. Writing is seen as an individual act allowing for private exploration, reflection and expression of thoughts and feelings [10]. To this end, participants were provided with open-ended questions asking about living with seizures.

2. Methods

2.1. Participants

Participants were approached consecutively and recruited from outpatient neurology clinics at the Royal Hallamshire Hospital, Sheffield (United Kingdom). Participants were also recruited through membership-led organizations for individuals experiencing seizures (see acknowledgements for the list of organizations). Recruitment took place between October 2015 and September 2016. The North of Scotland Research Ethics Committee granted ethical approval for this study.

Participants were included if they were over the age of 18 years, had a diagnosis of epilepsy, were able to provide informed consent, and complete a demographic and clinical questionnaire without help. All participants self-reported their diagnosis. The diagnoses of participants recruited at the Royal Hallamshire Hospital were confirmed by review of their hospital records. When possible, confirmation of the self-reported diagnoses of participants recruited through membership-led organizations was sought from their General Practitioner.

2.2. Data collection

This dataset was collected in the context of a randomized control trial investigating the effects of an expressive writing intervention for individuals with seizure disorders. The current study is based exclusively on data from participants allocated to the *intervention* group.

Participants recruited from outpatient neurology clinics were sent a participant information sheet at least 48 h before their appointment with a Consultant Neurologist. On the day of their appointment, individuals were approached and invited to take part in the study. Those who gave written consent were asked to complete a set of self-report measures. Participants recruited from membership-led organizations replied to an advert for a study of a writing intervention designed to help individuals with seizure disorders. Potential participants then contacted G.R. who gained written informed consent and provided access to an online form allowing participants to complete the self-report measures.

All participants were then given four writing booklets. Each booklet contained writing instructions, space for writing (four sheets of A4 lined paper) and a link to a website if participants preferred typing to handwriting. Participants were asked to produce four pieces of writing: 1) their very deepest thoughts and feelings about their condition [11]; 2) a letter to their condition [10]; 3) a letter to their younger self [12]; and 4) about a personal value and why it is important [13]. The topics had been set based on previous studies of writing therapies in other patient and non-clinical groups. Participants were asked to write for at least 20 min per question, at home and in private.

2.3. Measures

Participants completed a demographic questionnaire that recorded their age, gender, employment status and years of education. Participants' HRQoL was investigated using the NEWQOL-6D [14]. This is a six-item HRQoL measure specifically developed for individuals with seizures. A higher score represents a better HRQoL (0.96–0.34). The Generalized Anxiety Disorder (GAD-7) was used to measure anxiety [15]. This is a seven-item scale used as a screening tool and severity measure of mild (score of 5–9), moderate (10–14) and severe anxiety (>15). The Neurological Disorders Depression Inventory for Epilepsy (NDDI-E) was used to measure depression [16]. This is a six-item scale screening for major depression in people with seizures. Scoring above 15 suggests a current major depressive episode. Seizure frequency and severity were investigated using the Liverpool Seizure Severity Scale questionnaire (LSSS-3) [17]. This is scored from 0–100 with a higher score representing greater seizure severity. Participants were also asked how long they have experienced seizures, the date of their last seizure, and if they were currently taking any anti-epileptic drugs (AEDs).

2.4. Data-analysis

Participants' answers to each of the four questions were read separately, but as individuals expanded on experiences mentioned in their initial writings in later sessions it was decided that their written responses to all four topic prompts would be considered together in the analysis. The qualitative approach was guided by the methodology of thematic analysis [18]. This method was based on a mixed inductive (themes were grounded in the data) and theoretical approach (themes were influenced by the literature). The data was analyzed in six steps (Table 1). In the results section, the main themes are presented in the order in which participants often structured their written accounts. For instance, participants began their narratives by describing when they first developed epilepsy (Theme 1: Seizure onset), followed by what they experienced during ictal events (Theme 2: Seizure symptoms). Where possible, sub-themes are presented in logical order, for example, *onset* followed by *reaction*. Participants' quotes are represented by ""; any spelling errors in the quotes used have been corrected.

3. Results

The writings from twenty participants (17 female) were analyzed. Eight participants were recruited from outpatient clinics. All participants were from the UK. Overall, the median score of participants on the measure of HRQoL was 0.77 and seizure severity 51.3. 30% of individuals scored above the cut-off for likely major depression. 65% participants scored above the cut-off for likely mild-, 10% for moderate- and 10% for severe-anxiety (see Table 2 for further demographic and clinical details).

Five main-themes and 22 sub-themes emerged from the data (See Fig. 1). The five main themes reflected experiences of: seizure onset, seizure symptoms, treatment and outcome, living with epilepsy, and displays of coping (Table 3).

Table 1
Stages of thematic analysis.

Stages	Action(s)
1	To become familiar with the structure and content of the narratives, G.R. repeatedly read all participants' narratives.
2	G.R. imported and extracted, into NVivo, initial codes. This was a timely and iterative process that involved having to go back through narratives to re-code as new codes emerged.
3	G.R. compared and collated codes to create main and sub-themes.
4	Reviewed the themes and codes to define sub-themes. It was at this stage that the themes were shared between the authors allowing for changes. Thematic saturation was not possible as participants were not directed in their narratives and so they could choose to write about anything. However, all narratives were read one final time to make sure no more themes emerged.
5	Further refinement of sub-themes, assigning clear titles and definitions.
6	Writing the report, making the explanation of themes and sub-themes coherent.