

## Written accounts of living with epilepsy: A thematic analysis



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### ARTICLE INFO

#### Article history:

Received 10 March 2017

Revised 13 April 2017

Accepted 13 April 2017

Available online xxxx

#### Keywords:

Epilepsy

Qualitative

Thematic

Subjective experience

Phenomenology

Coping

### 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

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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.

**Table 2**  
Clinical and demographic information of participants.

P	Age	Gender	Years in education	Employment	No. of seizures in the last 4 weeks	Years since onset	Diagnosis confirmed	Taking AEDs
1	57	F	11	Unemployed	1	35	Y	Y
2	25	F	15	Benefits	3	20	Y	Y
3	52	F	–	Unemployed	1	1	Y	Y
4	50	F	11	Benefits	10/11	50	Y	Y
5	57	F	18	Benefits	7	35	Y	Y
6	36	F	15	Employed	5	26	Y	Y
7	40	F	11	Benefits	0	25	Y	Y
8	54	M	12	Benefits	0 (3 in the last year)	2	N	Y
9	58	F	11	Employed	0 (last one in 2012)	47	Y	Y
10	30	F	20	Benefits	2	16	Y	Y
11	59	F	17	Unemployed	0 (last one in 2014)	2	N	Y
12	27	F	17	Employed	0 (0.5 a month)	12	Y	Y
13	71	F	14	Pension	4	40	Y	Y
14	62	F	14	Benefits	2	45	Y	Y
15	53	F	20	Self-employed	1	52	Y	Y
16	34	F	12	Employed	0 (2 a year)	20	N	Y
17	70	M	14	Pension	22	55	N	Y
18	33	F	26	Employed	0 (1 a month)	16	Y	Y
19	58	F	–	Employed	0 (last one in 2013)	4	N	Y
20	44	M	11	Benefits	5	39	Y	Y
Median/%	52.5	F: 85%	14		1	25.5	Y: 75%	Y: 100%

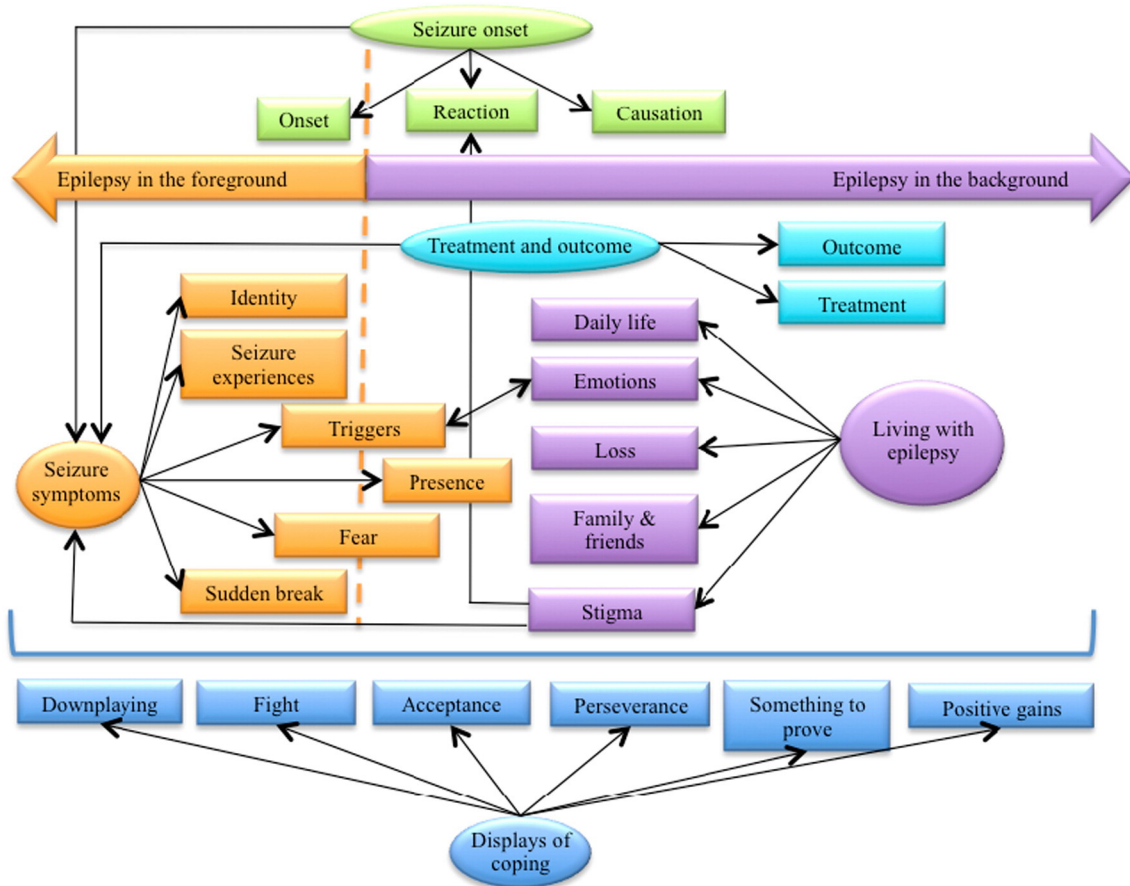
P = Participant, F = Female, M = male, AEDs = Anti-Epileptic Drugs, Y = Yes, N = No.

3.1. Theme 1: seizure onset

3.1.1. Onset

Sixteen participants began their narratives by describing when they first started to experience seizures. It was evident that developing

seizures was a significant moment with participants describing it as a “new chapter” or “total reversal” of their life. Individuals explained, in detail and chronological order, the events and short-term consequences. Participants would often report at what time in their lives they first experienced a seizure (Q1–4).



**Fig. 1.** Thematic map showing five key themes (represented by circles) and 22 sub-themes (represented by squares). Each color represents a different theme. *Epilepsy in the foreground* signifies the seizure events themselves. *Epilepsy in the background* represents the finding that individuals have to manage the effects of epilepsy on a day-to-day basis (i.e. constant presence of seizures, restrictions and stigma), which appeared to not be directly linked to seizures.

**Table 3**  
Emergent main-themes, sub-themes and illustrative quotes (Q).

Main-theme	Sub-theme	Illustrative quote
Seizure onset	Onset	"I would like to begin by telling of how my epilepsy first hit." (Q1)
	Reaction	"I was newly married, expecting my baby and suddenly I had huge fit, much to the shock of my husband." (Q2)
	Causation	"My epilepsy may have been caused by a car accident ... I was aged 5" (Q3); "I was diagnosed with epilepsy since 1 ½ years old ... I had fallen off a little mechanical horse in a supermarket" (Q4)
Seizure symptoms	Identity	"But they don't know my beast – they don't know the animal that lurks in the shadows" (Q5); "Sneaking up banging me on the back of my head" (Q6)
	Presence	"It prowls and it follows. At first it started toying with me – showing it's claws in those shadows" (Q7); "I've got to take you [seizures] with me everywhere" (Q8); "You [seizures] just hung around like a rancid fart." (Q9)
	Triggers	"I often take energy drinks with a quantity of caffeine in to maintain consciousness" (Q10); "Now, because in the past, exercise has triggered fits, I can only walk to exercise" (Q11)
	Seizure experiences	"... simple partial seizures – I am fully aware, just slightly spaced out, not with it .... A different type would be a gastric feeling from the stomach followed by a spaced out feeling." (Q12); "one minute I was spinning around and the next I was laid on the grass with a man holding my head up looking very worried." (Q13)
	Sudden break	"I remember one time when I was just coming round and the first aider came in and looked at me and said, 'do you not think I haven't got enough to bloody do without this?' Everyone was stunned and shocked but I just laughed ... it was so lovely to see someone having a laugh about it like it didn't really matter." (Q14)
	Fear	"Don't be scared though, it's not as bad as you think" (Q15); "This made me feel terrified at the thought I could be worrying people I loved" (Q16)
	Treatment and outcome	Treatment
	Outcome	"I don't know what my future will be, I know I will always have you [seizures] with me" (Q19); "I am a very determined and resilient person. One day, I will finally see the back of you [seizures]" (Q20); "It defines me, it's part of who I am, my identity ... I'm Ruth, the graphic designer, the long distance runner and epileptic" (Q21)
Living with epilepsy	Daily life	"It's bloody hell having epilepsy due to the uncertainty" (Q22); "... at the end of the day I have to admit it [epilepsy] rules everything I think and do" (Q23)
	Emotions	"I don't know how I am suppose to be happy with you [seizures] in my life" (Q24); "There have been times I've screamed at you [seizures] in frustration (literally from the tops of hills or the middle of woods) of the depths of despair" (Q25); "I'm getting angry, but today I'm feeling more positive, I don't know why and I won't be beaten." (Q26)
	Loss	"I always tell my partner Paul or my daughter Mary if I'm leaving the house and where I'm going" (Q27)
	Stigma	"...the diverse feelings and symptoms I had were just weird and to be hidden, something I found shameful" (Q28); "People think I can't work or that I'm stupid – my local neurologist is amazed that I work a 40-h week and get by" (Q29)
	Family and friends	"Frank [her partner] ... He is a great support who understands about my seizures and provides constructive, emotional, humorous help, we have a great caring relationship" (Q30); "I don't talk about it, the epilepsy, with anyone. I don't feel like anyone would understand" (Q31)
Displays of coping	Downplaying	"... in the grand scheme of things my epilepsy isn't that bad" (Q32)
	Fight	"I'm still fighting" (Q33); "Julius Cesar was only one person who overcame it [epilepsy]. He conquered all over the place. I got my driving license back this week - I am going to conquer my fears" (Q34)
	Perseverance	"I never let it [epilepsy] stop me" (Q35); "I don't let it [epilepsy] bother me though, what's the point? I never let it stop me being young and enjoying life" (Q36)
	Acceptance	"But again just accept it [epilepsy] and get on with life" (Q37); "I don't hate you [seizures], I think I just accept you with that extra caution about the risks" (Q38); "At first it bothered me that I couldn't run like the others, but then I just accept that's how it is and aim for my three miles, at least I have my music on and reach my goals, the same as everyone else!" (Q39)
	Something to prove	"I used to get involved in everything ... my sister said that I was only doing it to prove that I could do things, in hindsight I think she was probably right" (Q40); "I always worked very hard, always tried to be the best to prove to other people I was as good, or better than anyone else even though I had epilepsy" (Q41)
	Positive gains	"... having the seizures have helped me have confidence" (Q42); "I suppose because of you I did things to prove to others that I could – whereas my brothers and sisters weren't bothered to try" (Q43); "If I am only to have only half a life then I will make it count" (Q44).

### 3.1.2. Reaction

The onset of epilepsy provoked a range of reactions. Epilepsy may differ from other long-term conditions in that the onset is usually paroxysmal and not gradual. This was reflected in the narratives of four individuals whose first seizure was described as an abrupt disruption of their life plan (Q2), which did not make any sense because up until that point they were "healthy, happy and well". Three participants described an identity crisis as a result of developing seizures or being labeled as "epileptic"; individuals explained having perceived themselves as "different", "second-class", and less "important" or "worthwhile" compared to others. The initial onset was an "upsetting" and confusing experience. None of the participants described rejecting or doubting their diagnosis. In fact, for four individuals, receiving the diagnosis was a "relief" as it validated what they were experiencing. Three participants explained going through a gradual shift as their thoughts and feelings towards epilepsy changed over time. For example, they have become more worried because at first they thought their symptoms could be controlled by AEDs.

### 3.1.3. Causation

Five participants gave external, physical causes of their seizure disorder, or what they believed to be the cause (complications during pregnancy, car accident, traumatic brain injury or arteriovenous malformation) (Q3–4).

## 3.2. Theme 2: seizure symptoms

### 3.2.1. Identity

By instructing participants to write a letter to their seizures as a separate entity in session two, we will undoubtedly have encouraged participants to consider their seizures as having agency (acting independently). However, there was evidence in the other three writing sessions that participants tended to externalize their seizures and to discuss them as an intrusive independent agent that impacts upon them from the outside: "Mostly my seizure visits are simple partial seizures" [session 1].

Some participants described their seizures as being a separate phenomena from themselves; for example, giving their seizures a name:

“Bob ... because I need to call you something different from myself, something separate, something else – not belonging to me”. Participants would project human characteristics onto their seizures, for example, that their seizures are “toying” with them. However, the *otherness* of seizures could also give rise to more complicated experiences; in a piece of advice to her younger self one participant's letter explains: “it [epilepsy] doesn't have a character or a consciousness, it is part of you, you are not part of it” (Q5–6).

### 3.2.2. Presence

Seizures were often described as an ever-present and unwanted passenger that would sit “quietly in the background”, “stalk”, “prowl” or “follow” the participant around (Q7–9). Participants described that the feeling of this constant presence could perpetuate or maintain their anxiety. It was evident that there was a disparity between how participants' perceived their seizures and how they thought others did. Three participants made a reference to epilepsy being like an “invisible condition”, as between seizures others would think that there is “nothing wrong”, when in fact “it is always there, like a shadow”.

### 3.2.3. Triggers

Commonly reported triggers included stress, anxiety, fatigue, hormones, and sleep deprivation (Q10). Some participants explained that they developed their awareness of triggers over time or with age, while others described not being able to identify triggers any more. Triggers seemed to be linked to managing seizures. Participants would discuss behaviors that they avoided as a precaution, such as drinking alcohol and late nights (Q11). It seemed that participants would spend a great deal of their time worrying about events that may trigger a seizure.

### 3.2.4. Seizure experiences

Overall, 15/20 participants described some of their symptoms associated with seizures. This ranged from just describing postictal effects to going into great detail about what normally happens during their seizures (Q12). Others explained that their experiences were confusing as “they [symptoms] made no sense”; or that they have little or no memory of the events (Q13). Participants would discuss postictal symptoms such as confusion, memory-loss, pain, fatigue, anger and tiredness. The time needed to recover from a seizure varied, as some participants explained that they could carry on with their day as normal whilst others would be left “exhausted”. Seizure-related injuries were common as either a direct (“bit halfway through my tongue”) or indirect consequence (falls).

### 3.2.5. A sudden break

Seizures seemed to represent a transient break from normality that participants wanted to get over quickly so they could return to their normal life. Participants disliked the attention or sympathy from others; one individual explained that it makes her “feel guilty, weak and useless”. Some participants expressed a sense of resilience and of not letting seizures become a big deal (Q14).

### 3.2.6. Fear

Participants would often mention fear, but rather than this being described as a part of the seizure experience it was often discussed as an anticipatory fear, or stemmed from feelings about having a seizure (Q15). For example, when discussing the first seizure, losing control, “terrifying” witnesses of their seizure (Q16), the potential consequences (such as injuries), or being scared of triggers.

## 3.3. Theme 3: treatment and outcome

### 3.3.1. Treatment

A common theme was the perception of medication as an essential means of controlling seizures and achieving order, and predictability

(Q17). Participants seemed to view medication as something that they have to wade through in a process of “*trial and error*” to find the right drug or correct dosage. No individual described attending any psychological services to help manage with the challenges of living with epilepsy.

Whilst four participants described poor experiences with healthcare professionals (HCPs), the overwhelming majority reported HCPs as a valuable source of knowledge and noted them as providing support with managing their seizure disorder. Some participants discussed relying totally on HCPs, preferring a more passive role in the choice of AED treatment, whilst other participants (or family members on their behalf) would take a more active role, for example, questioning the doctor about their medication options.

The side effects of medication were discussed. In fact, some participants explained that their seizures are only of “*secondary*” importance as they are more affected by the potential consequences of epilepsy such as, memory loss, restrictions (i.e. not being able to drive), postictal symptoms or the side effects of AEDs (Q18). Side effects of the medication included: weight loss, dizziness, sickness, fatigue, lost memory and mood swings. There was a sense that participants seemed to view the side effects as a “*compromise*” they had to put up with in order to “*control*” their seizures.

### 3.3.2. Outcome

Expectations of outcome varied. Some participants described accepting that their seizures were a “*part*” of them (Q19). Others were defiant and “*determined to finally see the back*” of it (Q20). Some individuals explained that they “... *won't get rid of it*” (Q21). One participant who developed epilepsy at the age of five (now 44 years-old) wrote: “*If I could click my fingers and make you [epilepsy] vanish for the rest of my life I honestly don't think I would*”.

## 3.4. Theme 4: living with epilepsy

### 3.4.1. Daily life

It was clear that living with epilepsy was at times associated with great anguish, struggle and suffering (Q22). Epilepsy was described as something that could take “*control*” of or “*over*” their lives. Moreover, the consequences of epilepsy were not confined to seizures, instead affecting every part of life (Q23). For some participants, these problems were intensified during periods in which their seizures were particularly severe or frequent. Narratives were primarily focused on the consequences of epilepsy on daily life and social functioning, and not the actual seizures themselves. It was interesting that participants differed in how much emphasis they placed on the negative consequences of living with epilepsy. Five participants went into great detail about the challenges that they have experienced as a result of epilepsy (i.e. social, financial, personal and health).

### 3.4.2. Emotions

A central theme was the expression of negative emotion, most commonly depression (Q24), frustration (Q25) and anger (Q26). These emotions were expressed in the context of difficulties caused by epilepsy. Participants would discuss the negative consequences that living with epilepsy has had on their self-esteem. For some, this stemmed from being labeled as an “*epileptic*”, whilst others explained that their self-esteem improved in-between their seizures.

### 3.4.3. Loss

It seemed that epilepsy could directly take away participant's independence (e.g. by being scared of leaving the house) (Q27) or do so indirectly (i.e. not being able to drive). A common loss was employment. Some participants explained having to take early retirement, difficulties gaining employment, or lost their job. Having a career was linked to feeling like a contributing member of society or more independent.

#### 3.4.4. Stigma

17/20 participants noted epilepsy-related stigma or being treated differently as a result of their condition. This was a common source of distress. Stigma appeared to be associated with their symptoms (Q28) and with being labeled as an “*epileptic*” (Q29). Stigma could have wide and long lasting implications, for example, participants explained that they were unlikely to talk to others about their experiences or ask for help. Individuals described keeping their diagnosis a secret. Reasons for this secrecy varied: they did not want to be discriminated against, the embarrassment and shame, and that they felt it was not necessary as they were just as capable as someone without epilepsy. Some participants explained that they are upfront with people about having epilepsy or that they have managed to shake off the effects of stigma: “*I’ve stopped lying, I tell people*”. Reactions towards stigma did not seem to be related to the duration since seizure development or seizure frequency: “*... even though I had been seizure free for about 20 years, I was going to carry it [the stigma of the condition] to my grave*”.

#### 3.4.5. Family and friends

Family and friends were described as supportive in various ways (Q30). On the other hand, one individual explained that she feels like she gets more support from strangers than from those who are “*close*” to her. Participants described hiding their struggles from others as to not burden or upset them. A common theme was that participants felt like no one understands what they are really going through and how it affects their life (Q31). It was clear that friends and family also struggle; one participant wrote: “*It is always the one closest to an epileptic person who will suffer the most, I think*”.

### 3.5. Theme 5: displays of coping

#### 3.5.1. Downplaying

Participants often presented themselves as coping well with epilepsy. Whilst not diminishing the seriousness or consequences of their condition, participants would downplay or distance themselves from their symptoms, for example, by stating that they were “*lucky*” because it could be worse (Q32). Seven participants described the benefits of laughter or made jokes about their seizures.

#### 3.5.2. Fight

Participants seemed to conceptualize their life with epilepsy as a fight to not let it take “*a hold*”. Fighting terminology was regularly used: “*battle*”, “*fight*” and “*win*” (Q33). A narrative from one participant in particular typifies the fact that she perceives living with epilepsy as a fight when she used the metaphor of putting on her “*dog tags*” and referred to Julius Caesar as the mythic figure of a conqueror (Q34). Likewise, participants were determined to deal with the disorder and not let it “*hold them back*”. Past accomplishments would be discussed in the context that they were achieved “*despite*” having epilepsy.

#### 3.5.3. Perseverance

Thirteen participants exhibited a sense of resolve when discussing the challenges posed by epilepsy (Q35). Individuals seemed determined to manage and live well with the disorder (Q36). One participant illustrated this when describing her experience of trying to gain employment:

*“I went for 201 interviews and felt I was doing ok in some of the interviews until it came to the questions – ‘why did you leave your last job?’ as soon as I said it was because of epilepsy, people who’d been engaged and smiling no longer looked me in the face. It’s hurtful and makes me feel like less of a person ...”.*

The fact that the participant had gone to so many interviews knowing she is likely to be discriminated against demonstrated perseverance, but it is also how the participant responded to this rejection:

*“... But it also makes me angry. Like I said I’m stubborn. While doing research for my next degree, I stayed as a volunteer until they paid me and for the next 13 years”.*

In this narrative, the participant does not give up on the idea of finding employment, focus on the negative consequences of this experience or catastrophise by going onto discuss other times that she has been discriminated against because of her condition. Perseverance in the face of obstacles and adversity were consistently noted across participants’ writings, but also recurred several times within individual narratives.

#### 3.5.4. Acceptance

Although participants did “*fight*” against the consequences of living epilepsy, there were times when they had to accept that there are indeed limitations associated with the condition and therefore they had to adapt (Q37–38). However, when participants described being unable to do something due to their epilepsy, they would often employ strategies that seemed to assert the fact that they live a “*normal life*” and are self-autonomous: “*... although I have had to change my life to suite your [epilepsy] commands, I have done it in the way that was most suitable to me*”. For the most part, individuals appeared to have integrated epilepsy into their life (Q39).

#### 3.5.5. Something to prove

Participants seemed keen to present themselves as living a “*normal*” life or as someone who does not have a medical condition. Participants described wanting to “*prove*” that they are able to do something “*despite*” having epilepsy (Q40–41). As a result, it appeared that individuals sometimes struggled to get a balance of living a life that they would choose and being on a “*relentless drive*” to be the same as everyone else. It seemed that participants wanted to prove to others that they were still able. Having said that, given the finding that it was common for participants to hide their condition, these statements would suggest that they also had to prove this to themselves.

#### 3.5.6. Positive gains

Individuals discussed growing as a person through living with epilepsy (Q42). For some, epilepsy changed their identity, turning them into a different and more focused person (Q43). Other participants explained that the disorder had given them a new perspective on daily life (Q44).

## 4. Discussion

Participants typically began their narratives with a description of the events surrounding their first seizure. In response to developing epilepsy, individuals described feeling distressed, confused, and struggled with altered self-identities. Such reactions are consistent with findings from narrative research suggesting that the development of a chronic illness represents a *biographical disruption* in which aspects of everyday life are unsettled, forcing a re-examination of one’s identity, relationships and expectations [19]. These accounts give insight into the challenges that individuals may face after developing seizures, and highlight important considerations for how the communication of the diagnosis is achieved. For example, exploring patients’ perception of epilepsy from the very onset may help to manage attributions that are particularly problematic and to prevent difficulties such as self-discrimination, confusion, and negative emotion associated with seizures (i.e. anxiety about experiencing an episode in public) from ever arising in the first place. This would be likely to have immediate and cumulative future benefits in terms of the individual’s adjustment to living with the condition [20].

It was striking that participants demonstrated a tendency to focus their writings on the consequences of living with epilepsy as opposed to the seizures themselves. This gave the impression that epilepsy had a major and pervasive effect on daily life regardless of seizure frequency or severity. One example of this was that it appeared that epilepsy-related stigma was not associated to the duration of the condition,

seizure frequency or severity. Our findings resonate with those of previous studies suggesting that psychosocial difficulties can be more burdensome for individuals with epilepsy than clinical factors [3]. Despite this, in the current study it appeared that the care individuals received was primarily aimed at controlling their seizures. Whilst seizure remission is important, it seems that there is a need to move away from disease-focused models of care and instead, provide more holistic support involving multiple healthcare services. Clinical guidelines support the use of involving psychological interventions in the treatment pathways of epilepsies [21] that aim to help individuals deal with the various demands associated with the condition [22], as well as comorbid psychopathologies [23]. However, psychological support for patients with epilepsy is not accessible in many areas, even in developed countries [24]. Evidence-based brief manualised or self-management interventions are becoming more commonplace in care pathways of chronic illnesses [25]. The development of such treatments targeting specific challenges associated with epilepsy should be an area of future research [26]. The problems which such approaches should aim to tackle can be informed by statements from individual patients (such as those examined in this study), as well as from carers and clinicians [27].

Participants perceived HCPs as providing support with managing their seizure disorder. Whereas some participants appeared to take an active role in the management of their epilepsy, others preferred to remain more passive in their consultations with HCPs. The management of chronic illness requires a collaborative approach between the patient and HCP. Indeed, research has demonstrated how patient engagement can aid AED adherence in epilepsy [28]. Shared decision-making between patients and HCPs can have a range of benefits [29] and has become a policy objective of the National Health Service [30]. Therefore, attempts should be made to encourage patients to take an interest in health decisions, for instance by providing additional and personalized information, and encouraging individuals to take notes during or in preparation for consultations [31]. However, given that some individuals expressed a choice to defer treatment decisions totally to HCPs, there is also a need to develop a better understanding of how patients can be optimally involved in decision making in everyday neurological practice whilst respecting the wishes of those who want experts to make decisions for them [32].

An interesting finding was that, despite the reported difficulties associated with epilepsy, for the most part, participants were keen to communicate how “normal” their lives were and to present themselves as coping well with the condition. This observation mirrors the findings of a study which examined clinical interactions between patients with seizures and neurologists which demonstrated that eight out of nine patients with epilepsy employed a range of interactional and linguistic resources to portray themselves as in control and managing their condition [33]. Similarly, in another study examining doctor–patient encounters, patients with epilepsy were found to use references to other individuals who were not present during the conversation to normalize their seizure experiences (in contrast to those with psychogenic non-epileptic seizures who tended to use the same references to catastrophise) [34]. An important factor in the role of psychological adjustment to living with epilepsy is an individuals' perception, including self-efficacy. For instance, self-efficacy has been found to be negatively correlated with felt stigma, and positively associated with mastery and self-esteem [35]. Robinson [36] suggests that one approach to manage living with a chronic illness is to construct and live a story of a *normal* life. While it may be beneficial to possess and demonstrate the attitude that you *can* and *are* coping well with the condition, in the present study there were contradictions within individuals' narratives, suggesting that epilepsy could constitute a larger problem than patients are keen to let on. It is important to be perceptive towards such behaviors; for example, offering further support to patients even if they initially claim that it is not necessary, and not always taking patients' efforts to describe how well they are coping at face value.

#### 4.1. Limitations

There are many different approaches to analyze qualitative datasets. The method applied in the current study was thematic analysis. This approach fragments text into discrete categories as opposed to keeping the story intact. This means that we are unable to investigate the form or structure of individual narratives. Such narratological features have been shown to provide additional insights into how individuals comprehend and come to terms with a long-term illness and therefore warrant future investigation [37]. The nature of the questions will have had an influence on participants' writings, as well as their thoughts about their seizure disorders that they decided to share; for instance, in terms of conceptualizing their seizures as an independently active external agent. Having said that, this finding is consistent with previous research based on metaphor analyzes in transcripts of doctor–patient interactions [38,39]. It is another limitation of our study that the modest sample size did not allow us to distinguish between subgroups of patients with epilepsy, either on epileptological or psychological grounds. It would be good if future studies could make such distinctions, for instance between clusters of individuals with different self-reported attitudes towards their epilepsy [40]. Lastly, we did not seek participant's validation of our data analysis. This would have allowed participants to provide feedback on the interpretation and check for inconsistencies [41]. Conversely, the fact that participants knew that their writings were confidential, anonymized and they would not be contacted about the content of their narratives may have allowed participants to feel that they could be more open and honest.

#### 4.2. Conclusion

The purpose of this study was to further examine the subjective experience of epilepsy by thematically analyzing written accounts. Asking participants to write, as opposed to talk, about their experiences may have allowed individuals to have more control over their accounts. The findings of this study have implications for the treatment of epilepsy, including how the communication of the diagnosis is managed, as well as how the condition is treated. Although living with epilepsy has a profound impact on a range of psychosocial factors, it appeared that the care individuals received was primarily aimed at controlling their seizures. Our study suggests that more holistic support for individuals with epilepsy is needed.

#### Competing interests

None declared.

#### Acknowledgements

This work was supported by the Medical Humanities Sheffield (Sheffield University, UK). We would like to thank the following membership-led organizations for their assistance with recruiting participants: Epilepsy Action, Epilepsy Research UK, Epilepsy Scotland, FND Hope, FND Action, and the North East Regional Group.

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