

1-1-2020

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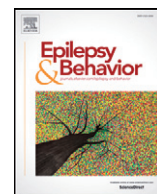
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### Recommended Citation

Kılınç, Stephanie; Campbell, Carol; Guy, Alison; and van Wersch, Anna, "Negotiating the boundaries of the medical model: Experiences of people with epilepsy" (2020). *All Works*. 2481.  
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# Negotiating the boundaries of the medical model: Experiences of people with epilepsy

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## ARTICLE INFO

### Article history:

Received 1 September 2019

Revised 16 October 2019

Accepted 17 October 2019

Available online 27 November 2019

### Keywords:

Epilepsy

Psychosocial support

Healthcare experience

Interpretative phenomenological analysis

Qualitative

Person-centered healthcare

## ABSTRACT

People with epilepsy (PWE) continually report dissatisfaction with the support they receive, particularly in regard to their psychological wellbeing. With its focus on optimal seizure control, epilepsy treatment is entrenched in the medical model of illness, despite growing evidence of the broader psychosocial impact of the condition. This study aimed to explore how PWE experience healthcare in the context of their lives. Semistructured interviews were conducted with thirty-nine adults with epilepsy from across the UK. An adapted version of interpretative phenomenological analysis (IPA) was conducted, and three superordinate themes were identified. Firstly, “negotiating the space between health and illness” identified how participants rejected the illness identity and struggled with a treatment regime, which reminded them of the longevity of their condition. Secondly, “tensions in adopting a biomedical perspective” considered how medical professionals overlooked the negative side effects medication had on participants’ lives, in favor of optimal seizure control. Thirdly, “the need for broader support” highlighted the additional psychosocial support PWE require. The findings indicate the need to incorporate person-centered, psychological services within the care pathway for PWE, as well as training for health professionals to recognize the broader impact of epilepsy beyond seizure management.

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## 1. Introduction

Epilepsy is classified by the Department of Health [1] as an intermittent and unpredictable long-term neurological condition (LTNC), which is characterized by recurring seizures. With 50 million people living with epilepsy worldwide, it is one of the most common neurological conditions [2]. The main form of treatment for epilepsy are antiepileptic drugs (AEDs), resulting in control over seizures in 60% to 70% of cases [3]. However, the side effects of AEDs are well documented: drowsiness; irritability; fatigue; muscle weakness; weight gain; problems with concentration [4]. Furthermore, given that seizure control is only possible using monotherapy in approximately 50% of cases, these side effects can be intensified [5].

To date, there is a predominance of biomedical research in the epilepsy literature, attempting to develop a definitive treatment for epilepsy [6,7] and aiming to identify the cause of seizures at the neurophysiological level [8,9]. Although such research is vital to attempt to identify the optimal seizure management strategy, a focus on the physiology of the condition neglects the psychological and social impact caused by seizures and epilepsy in general. Indeed, Kılınc, van Wersch, Campbell, and Guy [10] identified the way in which living with epilepsy

can produce a “ripple effect” (pp. 192) through a person’s life, affecting their work, relationships, social activities, and sense of self. Hence, the current study argues that to inform and improve service provision for people with epilepsy (PWE), research should focus on supporting PWE to live with their condition and develop a more holistic understanding of living with epilepsy.

Nevertheless, within western healthcare systems, the biomedical model appears to prevail in epilepsy management. Medicine’s construction of epilepsy equates the condition with seizure occurrence to the neglect of the broader impact of the condition, meaning, the psychological needs of PWE are largely unmet [11,12]. Concerns over the dominance of the medical model of illness are continually raised [13] in regard to the way it overlooks the role of psychological and social factors in both the development and treatment of conditions such as epilepsy [14]. Furthermore, the model is challenged by long-term conditions such as epilepsy, since recovery (that is, remaining seizure-free following withdrawal from AEDs) is rarely possible [15]. Medical practitioners focus on the aspects that they can control (for example, seizure occurrence through the development of drug treatments) while the psychosocial impact of such interventions on the patient is often overlooked [16,17]. Certainly, the current trend to track seizure occurrence in order to identify seizure triggers and optimize treatment regimes, neglects the “work” (pp. 5) required by and the emotional impact on PWE [18].

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Additionally, surveys repeatedly report that PWE want more information concerning how to adapt to the problems they face on a daily basis [19]. Studies also indicate patient dissatisfaction with the level of epilepsy-specific knowledge of healthcare professionals and concerns over accessibility to health services, continuity of care, and lack of information about epilepsy, treatment, and self-management [11]. Furthermore, 44% of PWE in the UK were admitted to hospital between 2014 and 2015; one of the highest rates of unplanned hospital admissions across the neurological client group [20]. Yet, such admissions would be unnecessary if the correct self-management support was provided for PWE.

Certainly, a shift towards supporting the self-management of epilepsy can be observed [21], encouraging PWE to take some responsibility and control for their condition. However, until recently, research examining the effectiveness of self-management strategies focused largely on their relationship with adherence to AED treatment (for example, Smithson, Hukins, Buelow, Allgar, & Dickson [22]). Epilepsy self-management interventions, such as Program for Active Consumer Engagement in Epilepsy Self-Management (PACES) [23], are beginning to focus on the psychosocial needs of PWE, adopting goal-setting approaches aligned with the person-centered healthcare agenda [13].

Nevertheless, epilepsy self-management interventions remain largely focused upon seizure control and tracking: adopting an information approach that conceptualizes self-management as a short-term activity, rather than recognizing its fluidity and longevity [24], fluctuations in epilepsy, seizure remission and reoccurrence, and changes in life circumstances and goals. Indeed, Johnson et al. [25] argued that strategies are often designed without conducting detailed needs assessment of PWE; hence, they may not meet their requirements.

Adopting a critical health psychology perspective to the investigation of the healthcare needs of PWE would provide the opportunity to examine the experience of living with the condition in more depth than it has been afforded to date, recognizing that the experience is interpreted by PWE in light of their social and cultural context [14,26]. Specifically, adopting an interpretative phenomenological epistemology can place PWE back in the center of the illness experience, as experts on the condition [27,28]. Interpretative phenomenological approaches allow researchers to ask critical, interpretative questions of the data, to examine how participants make sense of their reality [29]. They are concerned with the cognitive processes involved in meaning making [27,29], and the researcher must recognize that the participant may not express their thoughts and feelings easily [29]. This is particularly important when examining long-term conditions, such as epilepsy, since their accounts can represent their attempt to communicate their suffering in order to improve and potentially exert some control over their situation [30].

Consequently, the current study adopted an interpretative phenomenological approach and aimed to explore the healthcare experiences of PWE through an examination of their lived experience of epilepsy. The research question was, how do PWE experience their healthcare in the context of living with epilepsy?

## 2. Method

### 2.1. Design

Semistructured interviews were selected since they gave participants the opportunity to discuss their experiences in their own way while also offering the researcher the opportunity to probe issues further [29]. Since interpretative phenomenology is concerned with how participants construct meaning within their lives, the interviews allowed participants to explain their everyday experiences of living with epilepsy and their healthcare in detail and examine the meaning assigned to these experiences [31].

Following initial coding of the first round of interviews, follow-up interviews were conducted with twenty-four consenting participants.

This enabled reflection and further exploration of issues identified in round one [32]. Multiple interviews allow for further probing and can add depth to the analysis [33], as well as enhancing credibility through prolonged engagement [34].

### 2.2. Participants

Thirty-nine participants were recruited for the study (fourteen males and twenty-five females); twenty-four of whom consented to take part in the follow-up interview (six males and eighteen females). The sample was particularly heterogeneous: duration of epilepsy ranged from 1 to 49 years (mean: 15 years); age at diagnosis ranged from 18 to 57 years (mean age: 31 years old); 33.33% were seizure-free at the time of interview and those who were experiencing seizures had done so for between 1 and 37 years; 76.92% had idiopathic epilepsy; 79.48% experienced generalized seizures, while 10.26% experienced focal seizures, and 10.26% experienced both generalized and focal seizures.

The majority of participants (36 participants) were recruited through Epilepsy Action, via an advert on their website and newsletter. Three further participants were recruited through a local epilepsy support group. As such, participants were recruited from across the UK (including London, the Midlands, The North West, and North Yorkshire), although the majority resided near the study site in the North-East of England (76.92%). Participants were eligible to take part in the study if they had received a diagnosis of epilepsy between the ages of 18 and 59 years. This ensured that all participants were diagnosed in adulthood, since health services for children with epilepsy are structured differently and are arguably more comprehensive than adult services [35]. Additionally, participants were required to be taking AED medication, to ensure that they were still engaged within the healthcare system. Participant's names were replaced with pseudonyms.

### 2.3. Materials

The interview questions were designed to be open and nondirective [31], and the first round of interviews adopted an episodic approach [36] to enable exploration of the lived experience pre- and postdiagnosis and at the time of interview. Questions from the first interview schedule included the following: What did having epilepsy mean to you before you were diagnosed?; Can you tell me about the medical support you received?; What did it mean to be diagnosed with epilepsy? The second round of interviews were more probing of key issues and experiences discussed in the first round and included the following: What do you think can be done for PWE?; Would you ever consider changing your medication or your dosage and why is that?

### 2.4. Procedure

Ethical approval was obtained from a local University. The first round of interviews took place over an eight-month period, followed by the second round of interviews six months later (over a further six-month period). Interviews lasted between 20 and 70 min and were conducted either on the university campus, in a place convenient for the participants, or over the telephone. Although concerns have been raised over the use of telephone interviews [37], in this case, they resulted in richer, more in depth interviews, perhaps because of the additional anonymity afforded to the participants [38].

The analyst (SK) transcribed and reflected upon the first three interviews in each round before conducting further interviews. This ensured that the interview questions were appropriate. No amendments to the interview questions were necessary. Additionally, reflexivity was engaged with throughout the research process (via the use of a reflexive diary) to critically analyze the success of the interviews and reflect upon the research and analytic process [32].

A form of member checking was also conducted once the themes were finalized, to ensure the credibility of the analysis and interpretations [39]. There is debate over the relevance and practicality of member checking in interpretative analysis, since such analysis acknowledges that participants actively make sense of their reality during the interview process and, hence, may not be able to accurately confirm the interpretation [40]. The researcher is proposed to overcome this by producing an analysis that resonates with the participants, highlighting issues that are familiar to them [34]. Therefore, SK met with a local epilepsy group in the North East of England to talk through the key points from the analysis. All members of the group agreed that these reflected their lived experience of the condition and their healthcare.

## 2.5. Analysis

An adapted version of Smith and Osborn's [29] interpretative phenomenological analysis (IPA) was developed and utilized in the current study [41]. SK conducted the analysis, which began with line by line coding of each transcript, to enable microanalysis of the experience of each participant [42]. However, to avoid bias in interpretation of subsequent cases, development of theme ideas for each case was postponed until initial coding had taken place for each transcript [43]. Once the coding process was completed for all transcripts, initial theme development was undertaken, examining one transcript at a time. Clustering of emergent themes into initial themes then took place, followed by re-examination of each case, which considered any negative cases and theoretical concepts. The final themes were then reviewed and agreed upon by the other authors.

## 3. Results

Three superordinate themes were identified: negotiating the space between health and illness; tensions in adopting a biomedical perspective; the need for broader support. Information regarding the duration and cause of epilepsy, age at the time of the interview, and seizure type and control, has been included with each quote.

### 3.1. Theme one: negotiating the space between health and illness

The majority of the participants in the current study rejected the illness identity and no participant described themselves as sick.

...it makes me feel even worse than I already do because it's just another thing to add onto my health really, but em...

[Kirsty: interview 2, lines 97–98  
(1 yr, idiopathic, uncontrolled, generalized, aged 38)]

Em, it's not an illness is it? It's a, a condition in't it. An illness to me is like, I've just had a chest infection so I would say I was ill, you know, physically I was ill, whereas I don't know that epilepsy, it's not a disease, you can't catch it, so an illness to me is something you can catch. Although I would say cancer is an illness, but you can't catch that can ya?

[Tracey: interview 2, lines 256–261  
(8 yrs, idiopathic, uncontrolled, generalized & focal, aged 47)]

...Oh...em...its er, well, I see it as a...it's a condition like, em, you know some people are short sighted, it's just a condition.

[Lynne: interview two, lines 56–57 (1 yr, idiopathic, uncontrolled, generalized, aged 32)]

Kirsty was one of only a few participants to indicate that epilepsy was a factor involved in how she defined her health status. Through expressing that epilepsy was something to “add onto” her health, she did not explicitly recognize epilepsy as an illness but this description

does resonate with views of health and illness existing on a continuum, as fluid concepts. Others described epilepsy as being in the background of their life; a “nuisance” (Laura, interview two, line 58), which they lived with, which does not suggest that they saw themselves as ill. Furthermore, by differentiating between epilepsy as a condition and epilepsy as an illness, PWE seemed to regard illness as more severe than a condition. Participants such as Lynne felt that epilepsy was “just” a condition, implying that they believed illness to be more burdensome. Others struggled to define epilepsy as either an illness or a condition, since they conceptualized illness as a physical complaint that could be caught, a view that resembles the medical model of thinking. In their perception of epilepsy as a condition rather than a physical illness, it could be argued that PWE were attempting to negotiate whether they should be viewed as being sick. In this way, PWE can present themselves to others as healthy. In their reflections on their medical regimens, PWE again indicated that they did not view themselves as ill.

I can't say it's a burden because all I do is I take some tablets. Yeah I go back to the doctor's, check-ups now and again, but it doesn't really bother me that much.

[Michael: interview one, lines 362–364  
(21 yrs, idiopathic, uncontrolled, generalized & focal, aged 45)]

Ah...basically I've got epilepsy but if I take the pills I haven't got epilepsy, that's really what it boils down to.

[John: interview two, lines 68–69  
(8 yrs, idiopathic, controlled 7.5 yrs, generalized, aged 65)]

...the hope was that it was a one off and I wouldn't have it again. Then when it came back and I realized it was gonna be with me for good, erm...I was horrified, because I knew, I was horrified because of, the implications that it would mean. It was the tablets I think, the fact that I was gonna have tablets forever, and erm...it felt like a kick in the teeth, 'cos it was forever down the line.

[Hannah: interview two, lines 33–40  
(7 yrs, symptomatic, uncontrolled, focal, aged 36)]

The quote from Michael echoes earlier excerpts in the way in which PWE perceive epilepsy to be in the background of their lives, only in these cases this is attributed to the medication; the medication is their only reminder that they have epilepsy. This observation takes on further significance given that Michael's epilepsy was not controlled, and he still experienced generalized and focal seizures. Possibly, by focusing on his medical regime in this way, Michael was attempting to illustrate how epilepsy has little impact on his life, and therefore, he cannot be regarded as ill. John took this idea one step further, commenting that as long as he takes his medication, he no longer has epilepsy. His epilepsy was controlled as soon as he was diagnosed, and he had no further seizures once he started AED treatment; hence, an association between medication and seizure freedom is understandable, yet John does not consider seizures in this excerpt, he focuses instead on epilepsy. Although he had not experienced a seizure for over 7 years, this does not indicate that he no longer has epilepsy, only that it is controlled. Perhaps John was trying to demonstrate that he is healthy, rather than sick.

However, participants such as Hannah also described how their medication regimens reminded them that they had epilepsy and reflected their concerns with being viewed as ill. It is possible that taking medication interfered with their attempts to present themselves to the world as healthy, as well as serving to remind them that they were ill, throwing into turmoil their assertion that they were not sick.

Consequently, throughout the interviews, participants rejected the illness identity, preferring instead to describe epilepsy as a condition as opposed to an illness. Furthermore, their treatment regimens only

served as reminders of the long-term nature of epilepsy and were viewed as indicators to the world of their illness status. As such, PWE were seen to continually negotiate the space between sickness and health and appeared to reject the idea that they are ill in any sphere of their lives. This may be a consequence of the fluctuating and unpredictable nature of seizure occurrence and the absence of any other symptoms or signs of ill-health during seizure-free periods.

### 3.2. Theme two: tensions in adopting a biomedical perspective

The primary mode of medical management for epilepsy is AED treatment, although the way in which participants discussed having to take medication on a daily basis suggested some resentment towards the indefinite course of this approach. Participants highlighted a tension between achieving a balance between using their medication to manage and limit seizure occurrence and being able to live their lives with a few medication side effects as possible.

Er, what does it mean to me now? I don't like it. Er, the medication... obviously...having to take this medication all the time. If you go out, if we go to the mother-in-law's you have to make sure you have tonight's medication. You've got to remember, epilim, er, you've got to have water in your bag, so if you're anywhere you've got to have your water. I mean, I go to Church, you've got to have your water to take your medication while you're there at night. Er, it would just be nice to not have it.

**[Louise: interview one, lines 284–291  
(25 yrs, idiopathic, controlled 7 yrs, generalized, aged 55)]**

I think it's because I've got more used to it now...and also the fact that I was determined not to become completely reliant on the tablets, because if I upped the dosage, that means that I'll never be able to cope without it, and I refuse to, you know, to be completely dominated by the tablets.

**[Claire: interview one, lines 177–181  
(4 yrs, symptomatic, uncontrolled, generalized, aged 53)]**

The way in which participants described the medication as ruling their lives, indicated that having to remember and make provisions to take their medication each day could take over their lives to an extent. Participants shifted from considering the impact of seizure occurrence on their lives towards the broader impact of having epilepsy and thus having to take medication indefinitely. A life dominated by a medical regime may, in turn, signify that PWE are ill, a state or identity they may not want to assume. Indeed, it was discussed in theme one how PWE reject classifying themselves as ill, yet taking medication on a daily basis may serve as a reminder or perhaps an indication to the outside world that they are sick.

Furthermore, Claire discussed how she would not increase her AED dosage in order to achieve some balance in her life between medical control of her condition and some form of self-control. Her concern that she would become completely reliant on medication indicated that she feared the longevity of her condition; to control her epilepsy on a lower dosage could mean that she may be able to exert some control over her condition in the future and thus live a life that was not dominated by AEDs. However, some participants considered the way in which the medical profession's focus on AED treatment can have a negative impact on PWE.

...but the unfortunate thing is, 'cos my doctor used to say, "how many seizures have you had?" and eventually I said I wasn't keeping a diary anymore because I'm too preoccupied with epilepsy, it's ruling my life and I don't want it to. I know that I have between one and three a week, sometimes it's more than that, sometimes it's

less, that's all you need to know, I don't need to be like counting them.

**[Tracey: interview one, lines 272–277  
(8 yrs, idiopathic, uncontrolled, generalized & focal, aged 47)]**  
I changed doctors about 4 times because I was getting nowhere with them...I was having 20 fits a day, and I was on 20 tablets, and because it was getting worse, and every time I went to see him it was "Take more tablets, take more tables, take more tablets"...

**[Sharon: interview one, lines 93–97  
(29 yrs, idiopathic, uncontrolled, generalized & focal, aged 54)]**

Initially it [medical support] was crap. If I'd had side effects from the drugs it would be like... "Oh, you're not taking the drugs, you're not complying". And I'm like, I'm quite honest, and if I don't comply I tell people.

**[Sue, interview one, lines 92–98  
(5 yrs, idiopathic, uncontrolled, generalized, aged 28)]**

A tension is apparent in these accounts as PWE are forced into adopting the medical model's focus on medication for seizure control. Within the medical model of epilepsy, the focus is centered on identifying the optimal dosage for seizure control, yet Tracey found this emphasis and, in turn, epilepsy itself, took over her life. In particular, Sharon lost faith in the medical approach, as indicated by her continually changing General Practitioner (G.P.), since their response to her continuing high seizure frequency was to continually increase her AED dosage. It, therefore, seems apparent that PWE do not want epilepsy to preoccupy their lives. Yet the focus within our society to achieve seizure control through medical means can serve as a constant reminder of their condition. In turn, Sue highlighted how the medical model's reliance on AED treatments may bias opinion when PWE report that the treatment is not working. As such, the emphasis of medical professionals on optimal seizure control through AED management could lead to PWE becoming dissatisfied with the care that they receive and disenchanting with the medical approach to epilepsy management.

You know, the other thing, once I was told I'd put on weight, and it was either well, take your medication and keep all your weight, or stop your medication and have your seizures...I felt well, you know, what do you do for the best...I mean, I didn't want to be overdosed. I'm feeling that tired all the time. Well, you know, that's one look out. You have to do it.

**[Rebecca: interview one, lines 333–342  
(2.5 yrs, idiopathic, uncontrolled, generalized, aged 46)]**

...so it was only a small reduction, but to me it was a greater risk for me falling asleep, like going on the train and visiting people 'cos if I go on a train I'd sleep past the stop, I know it would...I mean yes I still need a sleep but I've got more control, it's like I can have a sleep when I want to have a sleep and so now I can plan it, as opposed to this awful like drop sleep...it enables me to plan more and do more in my life, I can go and visit my friend and I can do that on my own now, I don't need to have somebody take me.

**[Rachel: interview two, lines 13–24  
(3 yrs, symptomatic epilepsy, uncontrolled, generalized, aged 40)]**

... he wanted me to take I think it was 40 mg a day, which is a very high dose, erm, but I said no, I'm not going to take that because it knocks me out enough already, I don't want to be a zombie, you know I want to live a normal life, so I said I would take thirty.

**[Judy: interview one, lines 216–220  
(22 yrs, idiopathic, uncontrolled, generalized, aged 47)]**

Throughout the interviews, participants considered the trade-off between taking medication and leading as full a life as possible,

including the impact of the AED side effects. What appears central to these accounts is the way in which PWE attempt to maintain a balance between taking medication and living their lives. Antiepileptic drug side effects can be more problematic than seizure occurrence for those such as Rachel, who commented that she had “got more control back” once her medication and consequently the side effects had reduced. It seems that this control not only referred to control over epilepsy but also her life, a life that was ruled not only by epilepsy but also by her medication. Many participants also discussed their dissatisfaction with the way in which medical professionals tried to adapt their treatment in order to achieve optimal seizure control, despite this interfering with the way they wanted to live their lives. Certainly, Judy noted how medical professionals do not always take these issues into account and instead focus on AEDs for seizure control, resulting in a particularly black-and-white view that PWE can either experience seizures or side effects. The medical profession's focus on medication neglects the broader needs of PWE, rather than recognizing the way in which PWE may strive for a balance between seizure control and medication effects. However, some PWE relied on AEDs as a preventative medical treatment.

That's my saving grace. That's how I feel about it, because I just feel that, if the doctor ever said to me that I need to come off it now, then I would be terrified that it happened again.....if you had to come off it, I would be just really frightened. It's almost like a security blanket.

**[Janet: interview one, lines 232–239  
(18 yrs, idiopathic, controlled 9 yrs, generalized, aged 39)]**

Yeah that was in June last year [a tonic clonic seizure] ...em...I think em, it made me realize that, you feel that the condition is under control when you're taking your medication and nothing's happening you think well, you know, it's under control and we're all fine, and then you realize that if you don't take your medication it is still there, sort of lurking underneath and you know, it's all fine when you're taking the medication on time, and you kind of forget that you've got the medical condition.

**[Lynne: interview two, lines 44–51  
(1 yr, idiopathic, uncontrolled, generalized, aged 32)]**

The participants appeared to rely on medication as a form of seizure control, despite earlier comments from some PWE that they resented medical professionals doing this. Certainly, these accounts illustrate how PWE often see their medication as a “safety blanket”, focusing on it as a way of exercising some control over their condition and, in turn, their lives. Perhaps this is a result of the dominance of the medical model within our society: PWE resent the focus on medication for seizure control since it neglects their broader support needs, yet within our society, they can become so entrenched in this model that PWE in turn come to rely on medication to control the condition. This would ultimately allow PWE some control over their lives. For example, the way in which Lynne described epilepsy as “lurking”, implied that the condition was waiting for her to make a mistake with her medical regime. In turn, she accounted for seizure recurrence as purely stemming from forgetting to take her medication, making no attempt to consider any other factors that may have influenced seizure occurrence.

Through their reliance on medication to treat the condition, PWE overlooked self-management strategies that they could also put in place in order to take more responsibility for their health in general. Indeed, only a small number of participants considered the ways in which they could manage their condition to some extent through monitoring and adapting their lifestyle.

...it means I'm more aware, of, em...what my body's about, so I'm more in tune with my body than I was before, so I'm more aware of when changes happen, because when a change happens...a change happens for me and I've got to be reasonably quick along the way about thinking about it because it might be something that

hasn't been set down. So, I think I'm more in tune with my body. I'm probably, still more cautious.

**[Hannah: interview one, lines 234–243  
(7 yrs, symptomatic, uncontrolled, focal, aged 36)]**

I just think having epilepsy, just means that erm, you're always accountable because you've got to remember that there is something kind of in the background you know, that you've got to be aware of.

**[Beth: interview one, lines 248–250  
(14 yrs, idiopathic, controlled 2 yrs, generalized, aged 45)]**

Some participants recognized the way in which their life choices and lifestyle could affect seizure occurrence. In particular, Hannah reported monitoring changes with her body as a means of understanding her body and the influence her actions could have on seizure occurrence. Additionally, and in contrast to the earlier comment from Lynne that epilepsy was “lurking” in wait, Beth described epilepsy as being in the “background”, suggesting that she does not see it as a threat given that she takes some control over her health on a broader level. As such, these participants took further responsibility for their health, rather than relying solely on AED treatment and, in turn, highlighted the role of self-management strategies for PWE.

Consequently, the medical model as applied to epilepsy appears insufficient for PWE in terms of their support needs. In turn, it may also serve to limit the efficacy of self-management and health promotion approaches to seizure control.

### 3.3. Theme three: the need for broader support

Whereas theme one highlighted the problems inherent in focusing on a medical approach to seizure control, this theme considers the broader support needs of PWE and, in particular, the relationship between PWE and medical professionals.

Very poor I'm afraid. Yes, it's lack of understanding. The medical staff, I think they treat everybody the same, and not as individuals. Yes, I found that er, I mean they don't listen to the patients, and as I say, everybody's different, and medication, you know, you need a different dose for everybody.

**[Judith: interview one, lines 270–274  
(16 yrs, idiopathic, controlled 1.5 yrs, focal, aged 60)]**

Huh. Not a lot at all, because they never could give you answers, they weren't there to...you were just a number.

**[Louise: interview one, lines 146–147  
(25 yrs, idiopathic, controlled for 7 yrs, generalized, aged 55)]**

Participants raised such concerns over the lack of individualized care for PWE. In particular, reference was made to the feeling like a number, rather than a person. Once again, it appears that the perception that medical professionals focus on medication regimes leads PWE to feel dissatisfied with the care they receive. This discontent was more profoundly evident when participants considered the information that they received at diagnosis.

...and I was completely unsupported, I was completely alone, which was a bit scary, and then my neurologist at the time was like “yeah you've got this, ok, thanks, bye”, and I was like, ok, I don't know what any of this means, got to use drugs forever and drugs had all sorts of side effects and I was like, oh ok. I'm not very good at being sick, I just

ignore and carry on working, so I was just like ok, I'll take the drugs and I can carry on working.

**[Sue: interview two, lines 84–90  
(5 yrs, idiopathic, uncontrolled, generalized, aged 28)]**

Erm, fortunately she'd [Consultant] had some, erm, epileptic background herself, erm, so I think that certainly helps with the trouble we have, with the two separate types of medication that I take going against each other, erm, so her support has been, I feel very lucky to have her after that neurologist who'd been so unsupportive.

**[Michelle: interview one, lines 154–159  
(4 yrs, idiopathic, uncontrolled, generalized, aged 37)]**

It was commonplace that the participants learned about epilepsy themselves, from either books, internet, or epilepsy support groups. This served to increase their dissatisfaction with medical professionals, such as their G.P. or consultant. Some participants described feeling "hurt" and "disappointed" (Patrick, interview one, lines 524 & 541) by the lack of information they received at diagnosis, with some reporting that this led them to feel depressed. Additionally, in the absence of detailed information about the condition other than the treatment approach, Sue found herself ignoring her condition, rather than coming to terms with it. In contrast, the comments by Michelle illustrated how seeing a medical professional with specialist epilepsy knowledge can enhance the experience of PWE. Nevertheless, rather than information on specific topics or issues, participants indicated that they would prefer to be offered the opportunity to learn more about the condition and explore the implications of epilepsy on their lives.

There's no sort of, I don't know that it's counselling that people need, but they need somebody, to talk to about how what they've just heard has made them feel, and to explain, you know, the, just to explain things more fully and understand how they're feeling, and they need to have available to them, where these people can get help and support, because I had to find out all that by myself.

**[Tracey: interview two, lines 296–301 (8 yrs, idiopathic epilepsy, uncontrolled, generalized & focal, aged 47)]**

...although you're in a fit, you can still hear. It seems to be that nurses and doctors have got it in their brain that if you take a fit you've got to watch the tongue and watch this and watch that. If you're going to bite your tongue you're going to bite it. If it's going to bleed outside your mouth it's going to bleed outside your mouth, and you'll know. The thing is, you need to know that there's somebody there. If you know somebody's there, you can feel peaceful, go through it, come out of it quicker.

**[Patrick: interview one, lines 345–353  
(22 yrs, idiopathic, controlled 8 yrs, generalized, aged 41)]**

These accounts illustrate how PWE require broader psychosocial support, as well as medical care, particularly when they are first diagnosed with epilepsy. They did not necessarily advocate counseling but would have welcomed the possibility to explore how they felt with someone who had some knowledge and understanding of the condition. However, the key finding highlighted by this theme is the need for PWE to be provided with support that extends beyond AED treatment and the focus on seizure occurrence. They require a holistic service that recognizes their needs from all perspectives and considers the condition within the context of their lives. Indeed, Patrick highlighted the tensions between the broader needs of PWE and the medical model's emphasis on the physical body, when he reflected on the preoccupation with first aid procedures and limiting the injuries resulting from seizure occurrence to the detriment of the psychological needs of the person.

#### 4. Discussion

This study aimed to explore the healthcare experience of PWE. Overall, the themes highlight how PWE struggle to live and come to terms with their condition within the medical model's narrow construction of epilepsy, with its focus on AED treatment and seizure control. This can lead to dissatisfaction with medical care, although the way in which the medical model diverts blame for seizure occurrence away from PWE, affords them a certain level of protection from their condition. Consequently, the medical construction of epilepsy as a seizure disorder causes tension for PWE: they want seizure management through AED treatment but not to the detriment of being able to live their lives.

Specifically, participants resented the focus on medication to achieve optimal seizure control, since it served as a reminder that they had to live with the condition, which we could interpret as a rejection of the sick role [44]. Indeed, the focus on seizure tracking was noted by participants, supporting observations by Ancker et al. [18]. Additionally, the side effects of AED treatment had the propensity to affect the lives of PWE equally, if not more so, than seizure occurrence; hence, some participants took control over their medical regimens in an attempt to negotiate the space between feeling ill and feeling healthy.

What was central to the experience of participants was the need to maintain a balance between seizure control and living their lives, yet they felt this was rarely recognized by medical practitioners. Adjusting AED dosage was considered by participants within the context of their lives, whereby seizure occurrence was viewed in light of the subsequent implications on their lives, such as being able to drive, while for others, the side effects of AEDs were deemed to interfere with their lives more than seizures. This highlights the importance of adopting a more holistic view of epilepsy, beyond seizure occurrence, which recognizes the broader psychosocial implications of the condition [10,13].

Furthermore, the dominant medical approach of striving to achieve optimal seizure control, neglects the broader support needs of PWE. However, adopting a biomedical model of epilepsy can also serve to renege their responsibility over seizure occurrence. Perhaps PWE are able to continue rejecting the idea that epilepsy is an illness since its broader impact is poorly recognized, given that it is not underpinned by the physical, observable symptoms demanded by the medical model of illness [45]. This highlights a further contradiction in the participants' accounts: resenting the way in which medical professionals focus on medication to the neglect of their broader support needs, while themselves adopting the medical model of AED management in order to avoid taking responsibility for their condition.

However, this limits the extent to which PWE engage with self-management strategies. This is particularly problematic given the focus on the development of self-management strategies for PWE [21]. Their engagement in self-management initiatives may be affected as a result of their reliance on the medical model of seizure management. Hence, the contradictions in the participants' accounts are unsurprising, given the contradictions inherent in healthcare systems that advocate person-centered care, yet which develop initiatives that are grounded in a medical model of symptom management [22].

To ensure the development of person-centered services for PWE, psychological services could be incorporated into the care pathway at the time of an epilepsy diagnosis. Some participants called for a service where they could talk to a professional about their condition. Given the medical profession's reliance on the medical model of seizure management, it could be advocated that they work with psychologists to adopt a more biopsychosocial approach [46] to care to ensure that the psychosocial needs of PWE are met: taking a holistic view of each patient's experience and implementing and reviewing appropriate self-management strategies.

Additionally, the medical profession's focus on seizure occurrence to the neglect of the broader support needs of PWE results in a lack of recognition of the balance between seizure control and being able to live a full life. As such, there is a need to educate health professionals on the broader

needs of PWE and highlight the way in which a focus on seizure control through AED treatment removes responsibility from PWE and negates the efficacy of self-management strategies. Psychologists could work with training providers to encourage recognition of the individual needs of PWE. Indeed, the current findings demonstrate that PWE want individualized information and the opportunity to learn about their own particular form of epilepsy within the context of their lives [10].

The decision to adapt the IPA procedure and identify significant statements across the entire sample before engaging in theme development enabled suspension of any preconceptions during theme development. Although the sample size was much larger and diverse than would normally be expected for IPA, it allowed for examining the themes across a broad range of participants, with varying causes of epilepsy, seizure types, and durations. It could also be argued that since some participants were diagnosed up to 30 years ago, their experiences may not reflect those of people recently diagnosed with epilepsy. However, participants with a more recent diagnosis discussed similar experiences, while member checking demonstrated that the issues raised remained relevant today.

However, future research could examine some of the key findings from the current study in more depth. For example, the sample comprised of a higher proportion of noncontrolled PWE, as well as those with idiopathic epilepsy. Although care was taken during the analytic process to identify any variations in the experience between these groups, it is possible that the findings may have been different in a sample comprising solely of either PWE whose epilepsy was controlled or those with symptomatic epilepsy. It may also be pertinent to follow a group of newly diagnosed PWE, to examine their healthcare experience in further detail.

In summary, the medical construction of epilepsy reduces the experience to seizure occurrence. While this is relevant to PWE in the sense that they hope to achieve seizure control through AED treatment, it can become overbearing. In particular, the focus on seizure control can take over the lives of PWE, while medicine's focus on medical control could also limit the extent to which PWE could engage with the world as a result of AED side effects. As such, the medical approach to seizure control can prevent PWE from achieving a balance between living their lives and managing seizure occurrence. Additionally, it can promote the neglect of self-management strategies and encourage PWE to relinquish responsibility for their condition and seizure management.

### Declaration of competing interests

Dr Stephanie Kılınc is a Trustee for the Tees Valley, Durham and North Yorkshire Neurological Alliance.

### Acknowledgments

The team would like to thank Epilepsy Action and the Tees Valley, Durham and North Yorkshire Neurological Alliance for their support with this research.

### Funding

This research did not receive any specific grant from funding agencies in the public, commercial, or not-for-profit sectors.

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