Epilepsy & Behavior 73 (2017) 189–196

Contents lists available at ScienceDirect

Epilepsy & Behavior

journal homepage: www.elsevier.com/locate/yebeh

The experience of living with adult-onset epilepsy

Stephanie Kılınç [a,*], Anna van Wersch [a], Carol Campbell [b], Alison Guy [a]

[a] School of Social Science, Business and Law, Teesside University, Borough, Road, Middlesbrough TS1 3BX, UK
[b] Zayed University, United Arab Emirates

ARTICLE INFO

Article history:
Received 25 March 2017
Revised 16 May 2017
Accepted 27 May 2017
Available online 21 June 2017

Keywords:
Epilepsy
Adult-onset
Experience
Phenomenology
Qualitative
Unpredictability

ABSTRACT

The incidence and prevalence of adults diagnosed with epilepsy is higher compared to those diagnosed in childhood, yet the experience of living with adult-onset epilepsy has rarely been examined. Hence, the current study took a phenomenological approach to examining the experience of living with epilepsy following diagnosis in adulthood. Semi-structured interviews were conducted with 39 people from across the UK, diagnosed with epilepsy between the ages of eighteen and sixty, at two points in time, six months apart. Phenomenological analysis identified three central themes: the unpredictability of seizure occurrence; the ripple effect; and re-evaluating the future. Despite the accepted consensus in the epilepsy literature that living and coping with epilepsy becomes more difficult the older a person is diagnosed, the current findings indicated that this is inadequate. Rather, it is more suitable to consider that those living with adult-onset epilepsy have a specific experience of the condition and particular support needs, given that they once lived their lives as people without epilepsy.

1. Introduction

Although epilepsy is one of the most common long term neurological conditions in the UK [1], the lived experience of this illness has received relatively little research attention. Furthermore, although epilepsy prevalence increases with age [2], adult-onset epilepsy is rarely examined. Indeed, a small number of studies have identified 'age at onset' as a predictor of quality of life (QOL), with 'older age at diagnosis' correlating with poor QOL [3–5]. Certainly Chung et al. [6] identified that people with epilepsy (PWE) diagnosed later in life coped poorly with the diagnosis, whilst those diagnosed earlier in life displayed "emotional hardiness" (p. 258). Additionally, despite some studies reporting findings from adult populations, there is inconsistency within samples with regard to whether they were diagnosed in adulthood, hence an examination of the experience of living with adult-onset epilepsy is necessary.

A comprehensive range of psychosocial variables, including self-esteem [7,8], emotional functioning [9,10] and social functioning have been found to negatively affect PWE in general, in populations across the UK and Europe [11], America [12], the Middle East [13], China [14] and parts of Africa [15]. However, the focus often centers around an examination of seizure-related variables. Indeed, seizure frequency and severity appear to be the most significant predictors of QOL [16–18], with high seizure frequency significantly correlated with poor QOL scores [19–21], with this observation reversed when seizure frequency decreases [22,23]. Furthermore, a number of seizure-related variables have been correlated with broader psychosocial concepts, such as seizure severity and social functioning [24] and the perception of stigma and seizure worry [25].

There is also a wealth of literature examining depression and anxiety in PWE. With one in three PWE experiencing depression, it is the most common comorbid psychiatric condition in PWE [26] and there is certainly considerable evidence that anxiety and depression are significantly associated with poor QOL [19,27,28], as well as predictors of QOL in PWE [29]. Although attempts to examine what moderates this relationship predominantly focus on seizure occurrence [30,31], Kwon and Park [32] found that one fifth of PWE who were seizure free for at least one year exhibited symptoms of depression, indicating that seizure occurrence is not the sole mediator of the relationship between epilepsy and mental health problems.

Nevertheless, there appears to be a bias in the current literature in favour of reducing the impact of epilepsy down to seizure occurrence. Furthermore, this evidence tells us little about the lived experience of PWE. Additionally, much of this research is quantitative in design (particularly QOL designs). Arguably, adopting such a positivist position only serves to isolate specific variables which may not be of importance to PWE in their broader illness experience [33] and limits how we see PWE making sense of their illness within their social worlds [34]. Furthermore, the complete epilepsy experience cannot be explored in depth [35]. Consequently, a qualitative approach is advocated to provide the opportunity to explore the meaning of the phenomena for the person and better understand their experience [36,37]. Kugelmann [38] regards illness as an experience, a mode of existence or "being"

* Corresponding author.
E-mail address: S.Kilinc@tees.ac.uk (S. Kılınç).

http://dx.doi.org/10.1016/j.yebeh.2017.05.038
1525-5050/

(p. 75), hence a qualitative approach will allow in depth exploration of the meaning of "being" ill, or in this case, "being" a person diagnosed and living with epilepsy.

Research which examines living with epilepsy has previously been advocated [39], whilst a review of current qualitative research by Rapport, Clement, Doel and Hutchings [40] highlighted the effectiveness of adopting a lived experience approach to epilepsy. A systematic review of qualitative research examining the impact of the condition on children and adults [41] highlighted concerns over the unpredictability of seizure occurrence, issues with employment and finances, relationships, independence and self-esteem. However, the depth of analysis was limited. Indeed, many of the qualitative studies continue in a similar vein as those adopting a quantitative approach; categorising their findings in relation to known concepts and thus failing to add further depth to their interpretations [42–44]. Certainly, Nijhof [45] cautioned that such categorisation will only lead to homogeneity in the research findings and limits our understanding of the epilepsy experience.

Indeed, a qualitative approach allowed Faircloth [46,47] to examine contradictions in accounts, such as the ways in which PWE originally commented on their ability to control seizure occurrence, whilst later discussing the overwhelming force of a seizure and the ultimate difficulty they had in preventing a seizure from occurring. Furthermore, Jacoby, Ring, Whitehead, Marson and Baker [48] identified the central role of loss in the experience of PWE, be it loss of confidence, independence or control, amongst others. Additionally, seizure control was found to be central in reducing loss, particularly through the way in which it increased the confidence of PWE and helped them to feel "normal" again. Finally, a recent narrative analysis of the exercise experience of people with epilepsy has highlighted the ways in which the condition interferes with their exercise routine on a daily basis [49].

However, qualitative epilepsy research predominantly focuses on specific issues, such as loss [48] or exercise experience [49], rather than the broader lived experience of epilepsy. Nevertheless, studies such as these demonstrate how choosing a qualitative approach to examine the experience of living with epilepsy can provide more insight into the condition than research has delivered to date. Certainly, focusing on the illness experience within a qualitative framework can allow examination of the relationship between the body, self and society [50,51].

Consequently, a phenomenological approach is advocated in order to produce an in-depth analysis of the meaning of living with adult-onset epilepsy [52,53] and produce rich descriptions of the experience [54]. A phenomenological epistemology can provide the opportunity to move beyond the mind–body dichotomy and can bring meaning to the study of health and illness, since it conceptualises "being in the world" (p. 10) [55] as an embodied phenomenon. Furthermore, this approach places participants in the center of the illness experience; recognising them as the experts on the condition [56,57]. Hence, the current study aimed to explore the experience of living with adult-onset epilepsy.

2. Method

2.1. Design

Semi-structured interviews were conducted to allow participants to recount their story in their own way, whilst also allowing the researcher to probe areas of interest raised throughout each interview [53]. Six months later, following initial analysis, follow-up interviews were conducted with willing participants. This strategy allowed time to reflect on areas of interest emerging from the first interviews and examine these in more depth [58,59], as well as providing an opportunity for prolonged engagement in order to enhance the credibility of the research [60].

2.2. Participants

Participants were recruited through an advert placed on the Epilepsy Action website and newsletter. A further three were recruited from a support group in the North East of England. Interested parties were asked to contact the lead researcher (SK) to ensure they met the inclusion criteria. Firstly, they were required to have been diagnosed with epilepsy between the ages of 18 and 59 years old. This ensured that participants were only able to access adult healthcare services at diagnosis, since older adults could arguably have a different healthcare experience given the increasing recognition of their specific clinical and psychological needs [61]. Secondly, participants were required to be taking anti-epileptic medication at the time of recruitment, since PWE who have successfully withdrawn from their medication would arguably have a different experience of the condition than those who are currently experiencing seizures or living with the threat of seizure occurrence [62]. No further restrictions were placed on the sample.

Thirty-nine participants were recruited in total (14 men and 25 women). They were diagnosed with epilepsy between 18 and 57 years of age, with an average age at diagnosis of 31 years. Duration of epilepsy ranged from 1 to 49 years (15 years on average). Additionally, 76.92% of participants were diagnosed with idiopathic epilepsy, with the remaining participants having developed epilepsy as a result of either a brain haemorrhage (7.69%), encephalitis (5.13%), head injury (7.69%) or a brain tumour (2.56%).

The majority of participants (84.61%) reported experiencing generalised seizures, with six (15.39%) having experienced focal seizures. However, 13 participants (33.33%) reported that they had not experienced a seizure for up to 30 years (eight and a half years on average) and one of whom was controlled immediately from diagnosis. The remaining 26 participants continued to experience seizures during the study period, meaning that they had experienced seizures for between 1 and 37 years (almost 14 years an average). Additionally, for those participants who were experiencing seizures during the study period, the majority experienced them on a weekly or monthly basis, although some could experience seizures on a daily or even a yearly basis. However, many participants did report variation in the frequency of seizure occurrence.

Finally, 24 of the original 39 participants consented to take part in a follow-up interview (6 men and 18 women). The demographic details were largely comparable across the first and follow-up interviews (see Table 1). The 15 participants who chose not to take part in a follow-up

Table 1
Demographic information.

		Interview one	Interview two
Total participants		n = 39	n = 24
Gender	Male	n = 14 (35.90%)	n = 6 (25.00%)
	Female	n = 25 (64.10%)	n = 18 (75.00%)
Age at diagnosis	Range	18–57 years	18–57 years
	Average	31.10 years	31.08 years
Duration of epilepsy	Range	1–49 years	1–32 years
	Average	15.23 years	13.79 years
Seizure type	Generalised	n = 33 (84.61%)	n = 21 (87.50%)
	Focal	n = 6 (15.39%)	n = 3 (12.50%)
Cause of epilepsy	Idiopathic epilepsy	n = 30 (76.92%)	n = 17 (70.83%)
	Symptomatic epilepsy:	n = 9 (23.08%)	n = 7 (29.17%)
	Brain haemorrhage	n = 3 (7.69%)	n = 2 (8.33%)
	Brain tumour	n = 1 (2.56%)	n = 0 (0.00%)
	Encephalitis	n = 2 (5.13%)	n = 2 (8.33%)
	Head injury	n = 3 (7.69%)	n = 3 (12.50%)
Seizures controlled	Total	n = 13 (33.33%)	n = 6 (25.00%)
	Time controlled:		
	Range	1.5–30 years	2–15 years
	Average	8.58 years	6.25 years
Seizures uncontrolled	Total	n = 26 (66.67%)	n = 18 (75.00%)
	Time uncontrolled:		
	Range	1–37 years	1–32 years
	Average	13.65 years	12.5 years