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Epilepsy, Identity and the Experience of the Body.

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Epilepsy, Identity and the Experience of the Body.

Abstract

Living with a chronic condition can challenge a person's identity, yet there is a paucity of research exploring this experience for people with epilepsy and particularly for those diagnosed in adulthood. Consequently, through an interpretative phenomenological approach, the current study aimed to explore what the experience of adult-onset epilepsy meant for a person's identity. 39 people with adult-onset epilepsy from across the UK, took part in up to two semi-structured interviews. A modified form of interpretative phenomenological analysis was conducted and identified three themes: 1) disarming the impact of seizures considered strategies used to control seizure occurrence and regain a sense of control over the body; 2) distinguishing the self from the body highlighted participants' attempts to separate their sense of self from the unpredictability of their bodies; 3) separating epilepsy from themselves demonstrated how participants externalized epilepsy from themselves in order to reject it as part of their identity. The findings highlighted that living with adult-onset epilepsy can challenge a person's sense of self and trust in their body, resulting in the adoption of various strategies to manage the threat to their identity. As such, practitioners must pay attention to the impact that adult-onset epilepsy can have on a person's identity and faith in their body.

Keywords

Epilepsy; Identity; Body; Control; Interpretative Phenomenological Analysis; Qualitative.

Word count: 5380 words

1. Introduction

The impact of living with a chronic condition such as epilepsy, is consistently observed in terms of how it challenges identity on a variety of levels [1, 2]. Living with a chronic condition throws into question a person's sense of self [3] and brings with it a permanent change to their sense of self, where their identity must now accommodate their condition [4]. Their sense of "who am I?" is challenged as they become a person *with a chronic condition*; a person *with epilepsy*. However, we know very little about what this means for people with epilepsy (PWE).

The relationship between epilepsy and identity has received most attention in younger people. In particular, the condition has been shown to have a negative impact on the self-concept [5] and self-esteem [6] of children with epilepsy (CWE). However, evidence suggests that as age at the time of diagnosis increases, the impact on identity may also increase. For example, Admi and Shaham [7] found that adolescents did not view epilepsy as central to their lives, contending that they were not sick, just normal people coping with a health condition, whose lives were "interrupted by seizures" (p.1184). In comparison, the participants in their early twenties considered the impact of the condition as more profound in terms of its implications for the future, such as, having a family and finding employment. As such, the impact of epilepsy may worsen as age of onset increases, hence, it would be inappropriate to draw comparisons between PWE diagnosed in childhood and those diagnosed in adulthood. Indeed, Kilinc, van Wersch, Campbell and Guy [8] identified that adult-onset epilepsy brings with it a specific set of challenges, yet there is a paucity of research focusing on this group in particular. Although some studies report findings from adult populations, it is often unclear when the participants were diagnosed with epilepsy, or samples included participants who were diagnosed in childhood.

Nevertheless, research examining adult populations also indicates that the impact of epilepsy on identity can negatively affect health-related quality of life (HRQOL) [9]. Furthermore, Collings [10] noted how PWE rated their current self less positively than their anticipated self without epilepsy. However, such studies focus

on specific constructs, rather than examining the impact on identity or sense of self in any depth.

Conversely, qualitative research has explored how themes concerned with fighting seizures and attempting to regain control over seizure occurrence can be considered to reconstruct identity [11], whilst Rawlings, Brown, Stone and Reuber [12] recently identified how PWE externalize their condition in an effort to protect their identity. Furthermore, Jacoby, Ring, Whitehead, Marson and Baker [13] identified seizure control to be central in reducing feelings of loss and increasing the confidence of PWE. Whilst these findings further our understanding of how epilepsy can have a negative effect on the identity of PWE, there remains scant research examining this in its own right, to the same level of detail as research examining the impact of chronic conditions on identity.

The concept of identity is often conceptualized specifically in terms of social identity. Indeed, Hosseini, Sharid, Ahmadi and Zare [14] identified that PWE experience shame, embarrassment and what they term, “identity loss” (p.228), yet there is an underlying focus on how these experiences are shaped by their social context, particularly since the sample was Iranian and the authors highlight the stigma associated with the condition in this region. Certainly, when diagnosed with a chronic illness such as epilepsy, not only does a person’s sense of self change but their concept of who they are within their social context is challenged [1]. However, whilst such discussions of social identity consider how people with chronic conditions attempt to preserve their desired social identity, they also reflect concerns with how the body allows them to function within society. Indeed, theorists such as Radley [15] and Frank [2] considered body failure to be significant for people with chronic illness and the negotiation of their social identity. If a person cannot exert control over their own body, what does this mean for their sense of self? The impact of body failure has been considered in relation to conditions where physical functioning is limited on a daily basis, yet for PWE the impact of body failure and lack of bodily control during a seizure period is arguably much more profound. For PWE a seizure can result in a complete lack of control over their body and/or their conscious awareness. However, we know very little about the impact of this on PWE and it has

been established that the unpredictability of seizure occurrence and subsequent lack of control is a key concern for those with adult-onset epilepsy [8].

Furthermore, Merleau-Ponty's [16] concept of the "corporeal schema" (p. 137); the proposition that we learn to perceive the world through our bodies and trust in the ability of our body to perform in the way we expect, may be of particular significance to adult-onset epilepsy. That is, if a person is diagnosed with epilepsy in adulthood, the condition may challenge their trust in their bodies. Indeed, Röing and Sanner [17] identified that concerns over living with a weakened or vulnerable body (including an unpredictable body) was a key theme of their meta synthesis of research exploring the lived experience of chronic conditions. In turn, they argued that this experience could negatively affect a person's identity. Although Viberg, Blenow and Polski [18] hypothesized that poor self-image in CWE resulted from their lack of trust in their bodies and Yennadiou and Wolverson [19] discussed how lack of control over their bodies and seizure unpredictability are concerns for older adults with epilepsy, the experience and unpredictability of losing control over the body has not been examined to date in any depth.

Certainly, Smith, Flowers and Osborn [20] argued that researchers have become overly concerned with the influence of society to the neglect of cognition and contended that we also think about our bodies, particularly in times of ill health, and that these thoughts can be uncovered by in depth exploration and interpretation of participant accounts. Consequently, a phenomenological epistemology can bridge the gap between the mind and body with its emphasis on "being in the world" [21] (p.10) as an embodied phenomenon. As such, the adoption of an interpretative phenomenological approach to the study of the experience of adult-onset epilepsy would produce an analysis which moves beyond describing the experience and would provide a means of exploring bodily experience and how the body interacts with one's sense of self [22]; echoing Bendelow's [23] interactionalist stance and ensuring that the physiological component of epilepsy is not overlooked.

Consequently, the current study sought to adopt an interpretative phenomenological approach to the exploration of adult onset epilepsy in order to examine what the experience of adult-onset epilepsy means for a person's identity.

2. **Materials and methods**

Thirty-nine people (14 men and 25 women) with adult-onset epilepsy were recruited through Epilepsy Action from across the UK, via their website and newsletter, whilst three participants were recruited from an epilepsy support group in the North East of England. To be eligible for inclusion, participants needed to have been diagnosed with epilepsy between the ages of 18 and 59. Average age of onset was 31 years old and one third of the sample reported that their seizures were controlled at the time of data collection.

[INSERT TABLE 1 HERE - FROM KILINC, VAN WERSCH, CABBELL & GUY 2017]

Participants took part in up to two semi-structured interviews in order to explore key issues in detail and add depth to the final analysis [24,25], as well as to promote prolonged engagement in the field [21]. In keeping with the phenomenological ethos of participant as expert [26], interview questions were designed to be open-ended and care was taken to avoid leading questions [27]. The first interview schedule was designed episodically [28], with questions exploring participants' experiences of epilepsy prior to diagnosis, through to the diagnosis period and the present day, in order to capture any changes in sense of self. In particular, participants were asked to reflect upon how they would describe themselves both pre- and post-diagnosis, as well as their experience of seizure occurrence. The second round of interviews explored key issues in further detail, such as how they would describe someone with epilepsy and how they felt about and coped with seizure occurrence.

Ethical clearance was obtained from Teesside University Ethics Committee and pseudonyms were provided for all participants, to maintain anonymity. All interviews were conducted by SK; some were face-to-face and others were conducted over the telephone due to travelling constraints and the geographical spread of the sample. For a full discussion of the participants, materials and procedure, please refer to Kilinc et al. [8].

2.1. Method of analysis

The approach to interpretative phenomenological analysis (IPA) outlined by Smith and Osborn [26] was adapted for the purposes of this study and conducted by SK. The analysis began with the coding process, whereby notes on the initial interpretation of the data were marked in the margins of each transcript. This allowed microanalysis of each transcript before examining the experience across the entire sample [22]. However, it is argued here that the initial, detailed focus on each case can limit induction and bias the analysis of future cases. Certainly, Smith and Osborn [26] noted that researchers should approach each new transcript with a fresh perspective and be open to emergent ideas, however, it can be argued that this is easier if the generation of theme ideas is avoided at this early stage in the analysis; an idea taken from Moustakas [29]. Consequently, at this stage in the analysis, the development of theme ideas for each transcript was avoided until significant statements were identified across all transcripts. Following this, initial identification of emergent themes began, followed by clustering of emergent themes into initial themes. Finally, each case was re-examined once the theme clusters were produced, in order to refine the themes in light of any negative cases that may have been identified and to consider relevant theoretical concepts. In this way, it was possible to avoid developing themes in light of existing concepts/theories from the epilepsy and broader chronic illness literature [30], producing an analysis which remained faithful to the experience of the participants. Following this process, the themes were finalized and discussed with the co-authors. All co-authors agreed with the final themes.

To enhance the credibility of the findings a form of member checking was conducted. In IPA participant agreement can be unreliable since participants may either not have insight into their behavior or may not wish to disagree with the researcher [31, 32]. Consequently, a North East neurological charity arranged for SK to meet with a group of adults with epilepsy to talk through the key issues and concepts which were identified in the analysis. Rather than discussing theoretical concepts, the themes were introduced in the context of what the issues meant for PWE and how they could be used to promote the specific support needs of PWE. During the meeting the group agreed that the themes were relevant to them and

reflected the experience of living with adult-onset epilepsy. Additionally, in order to establish the rigor of the study, a reflexive diary was completed by SK throughout the research process [33].

3. Results

Three themes emerged from the analysis: disarming the impact of seizures; distinguishing the self from the body; separating epilepsy from themselves.

3.1. Theme one: Disarming the impact of seizures

Firstly, it was established throughout the interviews that PWE struggled with the lack of control they experienced in light of the unpredictability of seizure occurrence and this subsequently affected their sense of self.

Erm...yes, erm, but it's also very, it's very, is very demoralizing because you don't...you don't have this control over your body, you know you don't know, your brain, your epilepsy is controlling you up to a point, yeah.

Judy, Int.1; lines 102-105; uncontrolled

...em...we all I suppose like to be in control of all things, never mind control of our own bodies and, the nature of epilepsy is that you lose voluntary control and that's probably the worst thing about it...if you can't control your own bodily movements then what hope have you got of controlling anything else in your life if you can't even control your own bodily movements.

Alistair, Int.2; lines 197-203; uncontrolled

The loss of control experienced during a seizure had a negative impact on participants' sense of agency and represented how they felt that epilepsy was in control of them to an extent. More specifically, this lack of control was intimately linked with the sense of having little or no control over the body, which, in turn, negatively impacted on the identity of PWE. Certainly, Alistair explained how being able to control one's body is a fundamental aspect of life and lack of bodily control has repercussions for how you attempt to live your life in general. Consequently,

many of the participants discussed specific attempts to control seizure occurrence and fight off seizures.

I think I'd be right in saying, that I try to, as I say try delay the, you know the fit grasps, so to speak. Understand when a seizure takes place, you basically fall to the ground. That's the situation. Erm, as I say, the muscles'll jerk involuntary. But erm, the times I recall being in bed asleep and it's woken me, feeling queasy, really trying to grasp erm, won't let it come on, really try to grasp meself and, I'd say that's all I can do really.

Paul, Int.1 lines 445-450; controlled

...you know if I'm with a friend or my boyfriend or my family, I just ask them to count slowly and that allows my brain to kind of retune it. Erm, if I'm watching television I have to turn it off, come down and then turn it back on again, and that seems to work, that's seems to allow my brain to sort of re...reset itself (laughs).

Lynne, Int.1; lines 142-146; uncontrolled

The techniques discussed by PWE often involved mentally challenging the seizure by concentrating on a different activity or willing it not to occur. Regardless of whether these methods are actually successful in controlling seizure occurrence, what is of relevance to this study is why PWE adopted these strategies. Examination of the form these techniques take, would indicate that PWE are attempting to exert some control over their bodies (specifically their brain): either directly, by "resetting" their brain or diverting its attention; or indirectly, by challenging and willing away the seizure, determined that it will not occur. Through these strategies, PWE could reconcile with themselves that they could exert some control over their bodies and subsequently regain a sense of agency over seizure occurrence and their condition.

Consequently, the lack of control over their bodies is a significant concern for PWE; a concern which has implications for their identity and sense of self. However, attempts to directly influence seizure occurrence were only one strategy adopted by

participants as a means of exerting some control over the condition, hence themes two and three consider alternative, more indirect strategies employed by PWE.

3.2. Theme two: Distinguishing the self from the body

In their descriptions of epilepsy, PWE distinguished between their mind or consciousness and their physical body (specifically their brain). They described the brain as “switching off” and used analogies of a fuse box or electrical circuit to explain what happened during a seizure.

...the only way I can describe it when you ask what is it, I say “well you’ve got a fuse box haven’t ya, in your house? In modern fuse boxes have switches, sockets upstairs, sockets downstairs, things like, and it’s just like if, a fuse in that fuse box blew it knocks all your lights out down stairs, and you go through, and you flick the switch back up and they all come back on”. That’s how epilepsy works, it just operates like a fuse, it blows a fuse and somebody’s come along, flicked the switch back on, you’ve come to and you’re back round, but very groggy. That’s the best way I can describe it.

David, Int.2; lines 107-115; uncontrolled

I think of epilepsy as like being a short circuit in an electrical thing. You know, the insulation breaks down and all of a sudden, you get a flash.

John, Int.1; lines 336-338; controlled

Adopting metaphors where the brain is conceptualized as an object which is switched on and off, allows epilepsy to be aligned with an acute model of illness, whereby the condition represents a brief closing down of the brain and once its functioning is restored, the epilepsy is no longer a problem. This strategy arguably served to separate or distance their conscious mind from the brain and, in turn, themselves from the unpredictability of their body.

However, as well as coming to terms with being unable to control their body, PWE also had to reconcile themselves with being unable to control their brain; the

part of our bodies which we associate with our mind; the part of the body which is often conceptualized to contain the elements of ourselves which constitute our character.

I'd be in bed and all of a sudden, the bed would start shaking, and my wife would jump up and switch on the light. Well, she'd find me in the fit and my brain had switched off...

Patrick, Int.1, lines 107-110; controlled

...it's quite terrifying, the fact that you know, you are absolutely, the very worst thing is the feeling that you have absolutely no control over, your mind, your body that's bad enough, but the fact that you are totally unable to control what's happening in your head is absolutely terrifying.

Jonathan, Int.2, lines 154-156; uncontrolled

John's depiction of the brain shutting down during a seizure could illustrate how PWE managed the experience of the loss of conscious awareness or control during a seizure period by associating it with a "shut down" in the brain. Since the brain is often conceptualized as the center of our consciousness, personality, memories and ultimately who we are, it is plausible that PWE make the distinction between the physical brain and themselves in order to rationalize that the inability to control their brain is not a reflection on their identity. In this way, a malfunction of the physical brain takes epilepsy one step away from the person and the self. Jonathan illustrated how the inability to control your mind could be much more significant for PWE.

Consequently, in describing epilepsy and seizures using concrete, physical imagery, some PWE were attempting to distinguish their sense of self from the unpredictability of their bodies.

3.3. Theme three: Separating epilepsy from themselves

In an extension of the previous theme, rather than distinguishing the brain from the self, a key observation throughout the interviews was the strategy of discussing

epilepsy as an external force; an entity; something which was not part of them but which invaded their body or space and took the person away during a seizure period. This way, during a seizure they were not themselves; the epilepsy had taken over. This was evident in the way in which PWE separated epilepsy from themselves, contending that epilepsy was not part of them.

He'd say, "what have you done now?", "I've scalded myself", "and how have you done that" and I used to say, "I don't know do I, I'm not there".

Sharon, Int.2, lines 201-203; uncontrolled

...I, well I just dread them, I fear them, I'm afraid I do fear them. I am terrified. It's the experience itself because its, it's like some pernicious alien force taking over your body and you have no control over it and basically, and then that alien force is trying to crush the air out of me, I cannot breathe, my muscles are twisted, em...I'm gasping for breath and that's just before I lose consciousness.

Alistair, Int.2, lines 178-183; uncontrolled

Descriptions of a seizure "coming" (Jonathan, int.2, line 141), a form of attack, taking over their body, illustrated how it was perceived as a negative force which entered their body during a seizure but which was not present at other times in their lives. PWE attempted to distinguish the condition from themselves, whereby during a seizure period, epilepsy took over their body and they themselves were no longer present. In describing epilepsy as an alien force, an entity which they could sense was coming to take over their body, PWE located epilepsy as an entity outside of themselves which pursues them and invades their body. In this way, PWE considered epilepsy as an entity which was external to them, which interfered or interrupted their lives for brief moments, rather than something which defined them and altered their sense of self. In turn, this conceptualization served to protect their identity; maintaining a distance between epilepsy and their own sense of self.

This distinction was further compounded by PWE often being unconscious or in an altered state of consciousness during a seizure, providing participants with verification that they were not present during the seizure period. It is argued that this

strategy allowed participants to deal with the unpredictability of seizure occurrence and ultimately the unpredictability of their body, through externalizing the condition. In turn, creating this distinction between themselves and epilepsy served to protect their identity. Certainly, in the following excerpt Julie illustrated how she felt unable to accept that epilepsy was a part of her.

Just because you feel like well...I just don't want it to happen, full stop, and I think that what probably makes it worse is there's nothing I can do to stop it. You just don't want that to be a part of you. So, you know, I do get depressed about that side of it. It's like "Oh God it's happened again". I suppose I don't want to accept that it is a part of me. I can't...I don't feel ready to do that yet.

Julie, Int.1, lines 176-181; uncontrolled

...I think it was my perception of myself image. I just had to adjust to the fact that I was, I was carrying something else, that there was another part of my personality.

Hannah, Int.2, lines 82-84; uncontrolled

No, it's just, it's something that I have not something that I am.

Lynne, Int.2, line 67; uncontrolled

For Julie, the acknowledgement of epilepsy as a part of her identity was something which she felt unable to accept. She could not reconcile herself with the unpredictability of seizure occurrence and therefore rejected the condition as something which was part of her. However, Hannah discussed how, through time, she came to accept how epilepsy was an integral aspect of her identity, explaining how she adapted her sense of self to accommodate epilepsy. Although Lynne was clear in distinguishing epilepsy from her identity, assuring us that epilepsy did not necessarily define her, she still acknowledged that it was something which she had to account for. In this way, these participants highlighted how it is possible for PWE (even those continuing to experience seizures) to reconcile themselves with the condition and move away from considering it as external to them, towards accepting that it contributes to their sense of self, although it does not define who they are.

4. **Discussion**

This study sought to explore what adult-onset epilepsy means for a person's identity. Central to the findings is the way in which PWE reconciled their sense of self in light of their lack of control over their bodies. Whilst the first two themes focused on the experience of seizures and the impact on the body, the final theme is concerned with epilepsy as a condition, yet they all highlight concerns and challenges in negotiating identity. Furthermore, each theme considers the strategies that participants adopted in order to protect their sense of self and deal with the lack of control over their bodies during seizure periods.

Although attempts to control seizure occurrence have been considered in the epilepsy literature, they were often only conceptualized as coping strategies [14, 34]. However, control attempts can be much more than this: they are attempts to negotiate identity. Though this has been suggested by some epilepsy researchers, such as Faircloth [11], Jacoby [35] and Troster [36], there has been little examination of this to date. However, the current analysis provided evidence of the role of control strategies in the negotiation of identity. Furthermore, these attempts were often associated with controlling the brain by resetting or distracting it. Although such strategies have been identified in previous studies [37, 38], the way in which the participants talked about epilepsy and seizure occurrence also highlighted ways in which they portrayed to the world that they were in control of their bodies, albeit to a small extent.

Additionally, through the ways in which the participants adopted metaphors of the brain as an electrical circuit, PWE used what Lakoff and Johnson [39] termed ontological metaphors, whereby it is argued that we can quantify and, therefore, better understand abstract experiences if we consider them in the context of specific objects. Certainly, throughout these themes PWE used a variety of metaphors to reconcile themselves with the unpredictability of their condition and ultimately their body. Furthermore, Sontag [40] discussed how illnesses were considered in terms of their physical impact on the body, such as cancer and tuberculosis affecting a person's energy. However, the brain is associated with our mind, our mental health

and, as such, being unable to control the brain may be viewed as an inability to control the mind. Hence, PWE may conceptualize the brain and seizures in physical terms, in order to distance their mind, and therefore, their sense of self, from the body.

Certainly, there is a wealth of research examining the use of language and metaphor by people living with chronic conditions [15, 39, 40]. However, the ways in which participants in the current study used metaphors to distinguish between their conscious self and their physical body, took the concept of using metaphor to another level. As well as separating epilepsy from their sense of self, PWE also distinguished between their physical brain as an objective, biological component and the physical site of their seizures and their conscious mind as the metaphysical location of their personality and their identity. That is, the notion that they had no control over their mind was unacceptable for some PWE, since it could imply that they had no control over their mental health, their identity, their sense of self, and so forth. This notion is supported by Ryan and Raisanen [41], who identified how younger PWE conceptualized the brain symbolically, as central to their identity and “selfhood” (pp. 219). Consequently, whilst seizures impacted upon their physical bodies, PWE distinguished this from their conscious selves and drew on their minds in their strategies to fight seizure occurrence and regain a sense of agency, in order to limit the impact of the condition on their identity.

Finally, the ways in which some participants described epilepsy as something external to them, served to separate the seizure, and ultimately the condition, from themselves, to limit the impact of the unpredictability of seizure occurrence and their lack of control over their bodies on their sense of self. Freund [42] proposed that when diagnosed with a chronic condition, people construct psychosomatic boundaries to protect themselves; dividing themselves from their body in order to deal with body failure [43]. By objectifying an illness, we are able to separate ourselves from it, to protect ourselves from a condition which is affecting our sense of self [44]. Conceptualizing a chronic condition such as epilepsy as an entity, located it externally to the person and their identity [45, 46, 47].

In these ways, PWE could demonstrate to the world that they were not responsible for their bodies during a seizure period. Although this strategy of externalizing a condition as a means of protecting identity is well documented in examinations of chronic conditions [43, 44, 46, 47], it has only recently been identified in PWE and discussed briefly [12]. Further examination of this strategy in PWE highlights the way in which a lack of bodily control can limit trust in the body; since we believe that we should be able to control our bodies [48], the inability to control when their body will experience a seizure can be perceived by PWE as a slight on their identity.

However, it can also be argued that these approaches can make the illness experience more difficult and potentially detrimental to wellbeing [40]. If an illness is seen as only an illness, rather than something to fight against and distance oneself from, then a person may cope better. Certainly, this was evident in the final quote of theme three, when Lynne distinguished between epilepsy as something she *had*, rather than something she *was*.

Nevertheless, it was proposed in the introduction to this paper that a diagnosis of epilepsy in adulthood could challenge a person's trust in their bodies [16]. Indeed, all three themes illustrated the ways in which PWE attempted to disarm the control which epilepsy held over them and their bodies. Although the concepts of fighting epilepsy and attempting to regain control over one's life are evident in the epilepsy literature, they are often only considered as coping strategies [14]. However, the issues raised in these themes highlighted how they are intimately linked with the attempts of PWE to come to terms with the lack of control over their bodies and the subsequent impact on their sense of self. Consequently, PWE attempt to reconcile their body and self through fighting seizure occurrence and attempting to make sense of it, to demonstrate to the world that they have some control over their bodies [15].

Through the application of an interpretative phenomenological approach [26], these findings have highlighted the impact of epilepsy and seizure unpredictability of the identity of PWE (particularly those diagnosed in adulthood). However, such a large sample size for IPA arguably limited the level of interpretative depth in places.

Furthermore, although the themes were identified across the sample, a large proportion of the supporting evidence came from participants who were still experiencing seizures at the time of data collection. As such, it would be pertinent to examine the impact of adult-onset epilepsy on identity and sense of control over the body in a sample who have been seizure-free for a considerable period of time. Additionally, further interpretative research is required which focuses on seizure experience. Data collection strategies, such as that adopted by Rawlings et al. [12], who asked participants to write a letter to their seizure, can develop our insight into the impact of adult-onset epilepsy on identity.

Nevertheless, the findings indicate that practitioners must recognize that people diagnosed with epilepsy in adulthood have lived life without the condition and as such, the diagnosis can cause a shift in their sense of self; challenging their identity and faith in their body. Although, some PWE did demonstrate that they could reconcile themselves with this shift in identity, in some cases they had lived with the condition for a number of years, hence there may be a place to support PWE in achieving this level of reconciliation much sooner. Certainly, Aujoulat, Marclongo, Bonadiman and Deccache [49] argued that allowing people with chronic conditions to provide a narrative of their history supports them to make sense of their experience. They contend that healthcare professionals should encourage people with chronic conditions to engage with such narratives, which, in the case of adult-onset epilepsy could focus on life both pre and post the epilepsy diagnosis. Indeed, Chow [50] found that narrative therapy can support stroke survivors to reconstruct their identity. As such, it may be pertinent to explore the feasibility of developing psychological support services specifically for adults diagnosed with epilepsy, which adopt a narrative approach.

5. **Conclusions**

The current study highlights that we need to pay more attention to the impact of epilepsy (particularly adult-onset epilepsy) on identity, both in practice and through further research. By adopting more interpretative approaches to the ways in which we explore the experience of living with epilepsy and seizure occurrence, we can

enhance our understanding of the implications for PWE and develop appropriate support strategies and services.

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