



‘A rollercoaster of emotions’: Reflections on growing up with epilepsy in Ireland

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ABSTRACT

Purpose: Childhood epilepsy can have lasting effects which extend beyond those attributed to seizures. Previous studies have explored the lived experience of childhood epilepsy, but to our knowledge, no study has afforded adults with a diagnosis of childhood epilepsy the opportunity to reflect on their experiences. In comparison with children, adult respondents have the benefit of ample time having lapsed in order to process their experiences and have greater linguistic competencies. The aim of this study was to retrospectively capture, via interview, adults’ perceptions of the impact of epilepsy during their childhood.

Methods: A semi-structured interview schedule was developed in collaboration with patient experts to investigate participants’ experiences of growing up with epilepsy in Ireland. Thirteen Irish adults aged between 18 and 35 years, who had their first seizure before the age of 16, were interviewed. Data was analysed using Big Q reflective thematic analysis.

Results: Three main themes and 14 subthemes were generated from the data. The main themes comprised (1) disenfranchised grief, (2) need to belong and (3) walking in my shoes.

Conclusion: All three themes demonstrated a common need for patient care that is cognisant of the child’s developmental stage and psychosocial health, and the myriad of factors that contribute to both. Information, resources and clinical engagement with children with epilepsy require the input of patients with current or past experience of childhood epilepsy to guide development. A co-production approach is needed to address some of the disenfranchised and isolating experiences recollected by our participants.

1. Introduction

Childhood epilepsy has life-long effects that extend beyond the disruption attributed to seizure activity [1,2]. These effects have been investigated using proxy reports typically from parents [3], quantitative assessments of quality of life [4–6] and qualitative methods eliciting children’s self-reported lived experience [7–14]. These studies evidence the negative impact epilepsy has on children’s independence, school performance and relationships with peers. Retrospective qualitative research has captured the experiences of adults with epilepsy coming to terms with their diagnosis, some during childhood [15] but, to our knowledge, no study has offered adults the opportunity to reflect on their broader experiences of childhood epilepsy, nor the opportunity to share their feelings and behaviours, which may have been difficult to express or disentangle in real time [16,17]. The present study explored

retrospective insights into childhood epilepsy, developed uniquely through hindsight [18]. The aim of the study was to retrospectively capture, via interview, adults’ perceptions of the impact of epilepsy during their childhood.

2. Methods

2.1. Recruitment and participants

Participants were recruited in Ireland via purposeful sampling from charities, epilepsy organisations and social media. Participants self-referred by completing a Google Form confirming they met the inclusion criteria of being (1) adults between 18 - 35 years, (2) with first seizure on or before 16 years, and (3) raised in Ireland. At time of interview participants could continue to experience seizures or be

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seizure free and could be taking any number of antiseizure medications. An age range of 18 to 35 years was chosen to minimise recall bias, mirroring previous research in this area [50,49]. Perceived intellectual ability was not considered a cause for exclusion. A total of thirteen adults (10 females, 3 males) participated with mean age 27.31 years (SD = 6.76). Nine participants continued to have active seizures weekly (n = 2), monthly (n = 6) and yearly (n = 1). Four participants were seizure free between one and ten years. Most participants experienced more than one seizure type (n = 8), four experienced focal seizures only and one experienced generalised seizures only. All participants took anti-seizure medications during childhood and continued to take at least one antiseizure medication.

2.2. Procedure

Ethical approval for this study was granted by the Human Research Ethics Committee (HREC) at [redacted for blind review]. A semi-structured interview schedule was developed in collaboration with, and piloted on, patient experts to explore participants' experiences of growing up with epilepsy in Ireland. This pilot yielded comprehensive responses indicating the suitability of the interview schedule. The topic guide is presented in Table 1. Interview topics were drawn from previous literature [19–21]. All interviews were conducted and audio recorded via Zoom in 2022 and lasted between 25 and 60 minutes. Participants were required to provide consent at the commencement of each interview. Interviews were transcribed orthographically, verbatim and imported in NVivo 12 Plus for analysis. During transcription, authors assigned pseudonyms to each participant and redacted any potentially identifiable information from transcripts.

2.3. Data analysis

This study adopted an inductive Big Q reflective thematic approach [22,23]. 'Big Q' research aims to explore meaning in context, that is, to examine patterns across the data whilst taking into consideration the wider social context in which the data were generated [22]. This approach embraces subjectivity as the researcher is deemed active in the production of research, co-creating an understanding of personal experiences with participants. Our analytic approach was underpinned by an epistemological framework of critical realism which posits that independent truths, though possible, are inaccessible due to the constraints of context [24]. As researchers, we accept that our participants experiences were true to themselves, in the context of their upbringing. Our analysis commenced with familiarisation and line by line coding of data by [redacted for blind review] with review by [redacted for blind review]. The lead researcher [redacted for blind review] was responsible

Table 1
Topic guide for people with epilepsy during childhood.

| Section | Item |
|---------------------------|--|
| Learning experience | ■ How did seizures effect your school life, if at all? |
| | ■ Did you tell your peers in school you had epilepsy? |
| Relations with peers | ■ Did your peers comment on your seizures? |
| | ■ Did you feel you were treated differently by peers or teachers because of your epilepsy? |
| Treatment and support | ■ Do you feel you were treated differently to your siblings by your parents because of your epilepsy? |
| | ■ Do you think you got the support you needed? |
| | ■ Do you feel that your epilepsy affected your siblings / parents / family dynamic? |
| | ■ Is there anything you know now that you wish you had known / were told about epilepsy when you were younger? |
| Understanding of epilepsy | ■ Do / did you feel you could live a life of your choosing? |
| | ■ What do you think were the biggest challenges about growing up with epilepsy? |
| Reflections on epilepsy | ■ What were the positives about growing up with epilepsy? |

for grouping codes into themes. Both codes and themes were then refined in an iterative process between the lead researcher and a second member of the research team [redacted for blind review]. Themes and subthemes are presented below in a narrative synthesis and in the context of relevant research, as recommended by Braun and Clarke (2021). In keeping with the epistemological, ontological and methodological underpinnings of this study, the sample size was determined by the richness and depth of data [22].

3. Results

Three major themes and fourteen subthemes were generated. Major themes include (1) disenfranchised grief, (2) a need to belong and (3) walking in my shoes. Themes and subthemes are summarised in Table 2.

3.1. Disenfranchised grief

Grief was explicitly cited by three participants as a response to their epilepsy; 'you're grieving for the life you think you could have had'. Grief is an intrinsic, physiological reaction to loss or bereavement [25]. Disenfranchised grief is observed when grief is not publicly acknowledged or socially validated [26] and can lead to feelings of disbelief, anger, yearning or depression. These feelings, cited by 12 participants throughout their interviews, were distinguished as being experienced and understood only by those who lived with epilepsy. Five participants spoke of initial and lasting disbelief in their diagnosis. For one participant, scepticism of their epilepsy diagnosis was associated with greater seizure control 'because I was seizure free for so long, I was like maybe I don't have it as much'. The nature of seizures also gave rise to uncertainty about their diagnosis, with one participant noting, years after

Table 2
Reflections on experiencing epilepsy during childhood.

| Theme | Subtheme | Illustrative quote |
|-----------------------|--------------------------------------|--|
| Disenfranchised grief | Disbelief | 'Sometimes I'd even think to myself well maybe this isn't even epilepsy' - Participant A |
| | What If? | 'How would it have been if I were able to think properly?' - Participant B |
| | Frustration | 'Why couldn't it happen to someone else? Why can't it happen to the kids that are bold?' - Participant C |
| | Depression | 'No one else cares about epilepsy so why should I?' - Participant D |
| | Acceptance | 'There's nothing wrong with having epilepsy...sure look everybody has something' - Participant E |
| Need to belong | Feeling different | 'At first I just thought I'm a weird person' - Participant F |
| | Isolation | 'I hardly talked to anyone and no one talked to me' - Participant G |
| | Change in identity | 'I became the mammy of the group' - Participant H |
| | Impact of support | 'Honestly if I didn't have my family I don't know what it'd be like' - Participant I |
| Walking in my shoes | Finding your tribe | 'Someone gets how I'm feeling, gets what I'm going through' - Participant C |
| | Fearful | 'The fear was drilled in very early on' - Participant J |
| Stigmatised | Stigmatised | 'It was [as if] someone was crazy because it's got to do with their brain' - Participant H |
| | Dynamics within microsystem | 'You kind of feel guilty, then, because everyone else is stressed and everyone else is worried, and you're not going to talk about it and I had no one to talk about it to.' - Participant K |
| | Developmentally appropriate practice | 'You don't have your full brain' - Participant L |

diagnosis ‘because of the fact that I only have absence seizures, sometimes I’d even think to myself well maybe this isn’t even epilepsy’.

Anger was also reported, sometimes within the context of what could be deemed as a resentment towards epilepsy. One participant wondered, for example, how they would have progressed in school had they been able to ‘think properly’. Another participant noted she did not ‘do bad’ in school, but ‘would have done a hell of a lot better’ without epilepsy. Another commented that she ‘would have been able to get out more, make new friends’ if she didn’t have epilepsy. Resentment was also experienced for future losses, with one participant commenting ‘I’ll never get these things that I would love to have and that’s because of my epilepsy’.

“I thought this is my life ruined already”

[Participant J, 32 years old]

Ten participants recalled feeling frustrated by epilepsy describing the experience as ‘a really big inconvenience’. Those whose aetiology was unknown found the diagnosis particularly frustrating as ‘you have to take medication for something, but you don’t know what’s causing the issue’. There was also a clear sense of injustice associated with their diagnosis.

“Couldn’t you just give it to a teddy or a doll? Couldn’t somebody else take it? Can someone else have it? I don’t want it. I do not want this. This is not fair. Why does it have to be me?”

[Participant C, 35 years old]

Although disenfranchised grief may be expressed in multiple ways, all participants reported experiencing mental health struggles during childhood. These experiences included depression, low self-esteem, fractured confidence and anxieties which in some instances led to panic attacks. Seizure activity, imposed social restrictions, loss of independence and school-related stress were attributed as contributors to these difficulties. One participant described being ‘so tightly wound because of everything’. Another, more dejected participant, commented ‘no one else cares about epilepsy, so why should I?’.

“It’s a mental health condition as much as it is a neurological condition”

[Participant K, 23 years old]

Although a diagnosis of epilepsy evoked a variety of negative emotions, a sense of needing to ‘get on with things’ was common. Eleven participants came to accept their diagnosis and refused to allow epilepsy ‘be a full stopper for living life’. As one participant acknowledged: ‘everybody has something’. For eight of these participants, the process of coming to accept their diagnosis was neither staged nor linear but rather a unique roller-coaster of emotions. Despite continued struggles with feelings of anger and depression with age, these 11 participants accepted their epilepsy in adulthood:

“This is part of me, I have other gifts, I have other talents, I have other abilities.”

[Participant E, 35 years old]

3.2. Need to belong

The need to belong is a fundamental psychological process that is central to social identification and group membership [27,28]. Deviance from the expectation of a group is often met with labelling and ostracization [29], experiences that can significantly impact psychosocial development [30]. Recalling their school years, 12 participants described how their epilepsy label immediately made them feel ‘different’, ‘weird’ or ‘strange’; that there was ‘something wrong’ with them. Five participants stated that they had never met anyone else with epilepsy and 12 participants described their experience during school as ‘isolating’. One participant recalled ‘no one talked to me’ and another

recalled ‘staying away’ from people at lunchtime in case of being ‘questioned’.

“I certainly blamed [epilepsy] on not being able to make friends”

[Participant J, 25 years old]

Four participants described a change in identity accompanying their diagnosis. Participants who described themselves as being ‘a high grade student’ or always wanting ‘10 out of 10’ found it difficult to have that ‘taken away’ when grades ‘started slipping’. Participants reported needing to ‘grow up a lot quicker’ than peers, notably when making decisions surrounding potentially risky behaviour such as restricting alcohol use. Ten participants described their diagnosis as an identifier; schoolmates ‘just knew me as the girl who has epilepsy’. The social constraints placed on one participant corresponded with a change in role to reaffirm their belonging within peer groups:

“I became the mammy of the group because then...everybody was [drunk] or whatever so I was minding everyone”

[Participant H, 34 years old]

The support of family and friends encouraged and facilitated the meaningful inclusion of participants in school and extra-curricular activities during childhood. While not all participants described positive experiences with classmates, friends were described by nine participants as being ‘supportive’, ‘understanding’ and ‘lovely about it’ when an epilepsy diagnosis was disclosed or a seizure experienced. The support of friends was notable for one participant who experienced a seizure during a youth training session. Though embarrassed to return the next week, text messages from ‘the girls...just like [to] make sure I was okay’ eased a return to the wider group. Immediate family members were also lauded for their ongoing encouragement and willingness to make adaptations to foster inclusion.

“They did the whole like highline thing, you know you go climbing, and I chose not to do that, but my brothers were like well, if you want, we can go and do like something else that you could be included.”

[Participant I, 20 years old]

The experience of connecting with people who also had epilepsy was considered extremely validating, giving participants comfort in the knowledge that ‘a lot of people’ had epilepsy. Eight participants described the connectedness felt among people with epilepsy, a group who ‘got’ how each other were feeling and what they were ‘going through’. Speaking to other people with epilepsy ‘boosted confidence’. In finding their tribe, these eight participants were reassured in the knowledge that they were ‘not the only one’ with epilepsy. As adults, six participants encouraged young people with epilepsy to engage with support groups as they would ‘learn more from each other than we’ll ever learn from doctors.’

3.3. Walking in my shoes

Children who are patients require information on their condition that is not only linguistically appropriate but is also cognisant of their socio-emotional state and unique family dynamic [31]. As children, 12 participants in this study reported struggling to fully grasp their diagnosis and its consequences. They described epilepsy as by ‘invite only’, meaning only those who were involved in its diagnosis fully understood the condition. As they attempted to navigate both school and family dynamics, 10 participants recalled feeling fearful, vulnerable and stigmatised by peers.

Seizures and their aftermath were associated with cascading fear; a fear which was ‘drilled in early on’. The experience of having a seizure as a child was described as ‘terrifying’. Seven participants described a ‘lack of control’ and a ‘fear that it could happen at any time...that I could get one at any moment.’ This fear was not limited to the person with

epilepsy. Four participants recalled how their parents were ‘so worried constantly’. Siblings were similarly distressed:

*“I ended up on the floor, and he got the fright of his life... My brother, all he had to say to me was ‘why the hell did you do it when we’re here on our own?’ [laughs] He was about 8 or 9, he was f***ing traumatized.”*

[Participant C, 35 years old]

Three participants also commented on experiencing the stigma of epilepsy during childhood. ‘Back then’ epilepsy was associated with ‘someone crazy because it’s got to do with their brain’. Nine participants encountered ‘ignorant’ classmates who reduced epilepsy to ‘the thing with the lights’. Seizure activity wasn’t recognised ‘unless you drop to the floor and start foaming at the mouth like a rabid dog’. One participant recalled encountering peers who thought an individual with epilepsy was ‘possessed’.

Seven participants described how, even as children, they recognised the effect of their diagnosis on their family. Family dynamics were ‘difficult’ due to the stress caused by seizures and could cause ‘friction’. Three participants recalled feeling guilty that epilepsy was ‘having such an impact on everyone’s lives’. In particular, they were conscious of the amount of attention they received while, in some cases, their siblings were ‘neglected’. In contrast, reflections of another participant highlighted how their diagnosis strengthened their family unit:

“I got to know [my mother] so well and that probably wouldn’t have happened if I didn’t have my epilepsy”

[Participant G, 35 years old]

Twelve participants commented that, as children, they didn’t fully understand their diagnosis or its implications. One participant reflected that it was ‘only later in life that I can really comprehend the struggles I was going through’. These experiences seemed to vary with age, with younger participants in this study recalling that their diagnosis was explained to them, while older participants described being left to their own devices: ‘I was given a book with images to describe the seizure... and that was it’. One participant highlighted how medical professionals would speak primarily to her parents while she wondered ‘what are you talking about?’ In contrast, younger participants were grateful that they were diagnosed during the digital era as ‘all the information was available...I didn’t feel that I couldn’t find answers’. Although participants recognised their own misinterpretations as children, they also cited comments from medical professionals which proved impactful and lasting:

“I was told by doctors...I could grow out of the epilepsy. And when you’re told that as a child... it actually traumatizes you because you think then well, on my 13th birthday, my 14th birthday it will stop. It will end. There’s an end in sight, you know? But that’s not true. I didn’t outgrow the epilepsy.”

[Participant M, 35 years old]

4. Discussion

Our participants’ recollections of their childhood epilepsy were thematically represented by disenfranchised grief, a need to belong and walking in my shoes. Although their diagnosis evoked emotions often associated with bereavement [32], the lack of a shared understanding of participants’ current and future loss may be arguably better represented as disenfranchised grief [33]. The second theme, the need to belong to a social group [27], was characterised by feelings of difference and isolation, but facilitated by the support of family and friends and finding the tribe of others with epilepsy. Our final theme, walking in my shoes collated participants’ experiences of fear, stigma, dynamics within the microsystem and developmentally appropriate practice; personalised factors that require consideration across clinical, educational and

domestic settings [34]. All three themes demonstrate a common need for patient care that is cognisant of the child’s developmental stage and psychosocial health, and the myriad of factors that contribute to both.

Research has illustrated how people with epilepsy experience a myriad of emotions in response to their diagnosis [15]. Although studies have described parental feelings of grief in response to their child’s epilepsy diagnosis [35,14] to our knowledge, our study is the first to acknowledge similar feelings among those diagnosed with childhood epilepsy. Acceptance of a diagnosis may be disrupted in the absence of the conditions necessary for loss to be processed [36] instigating a more complex cycle of symptoms [25]. Grief counselling may assist children in verbalising their loss, naming emotions, and making sense of their diagnosis [37]. As the very nature of disenfranchised grief precludes social support [38] all parties invested in the child’s treatment and care should be made aware of the emotions associated with and the various trajectories of adjustment to loss [32]. All adults also recalled struggling with their mental health as children. Greater awareness of mental health issues among this population is required by medical staff who may consider allowing extra time in clinic to acknowledge and address these issues. Parents may benefit from advice on how to shape thoughtful responses to expressions of grief, without the need to generate solutions or relief [39]. Providing such support has been evidenced to help patients accept their diagnosis [40].

Our subthemes relating to participants’ need to belong are mirrored in qualitative studies of young people with epilepsy [11]. Much like our adult participants, children with epilepsy have reported feeling different, isolated and socially excluded throughout their engagement with the education system [9,12–14]. While the impact of epilepsy on the development of young people’s sense of self is clear [41] the present study details how participants modified their social role in order to maintain friend-group membership. Considering the detrimental effects of peer rejection [42] the meaningful inclusion of children with epilepsy must be encouraged across educational and recreational settings. Social, personal and health education curricula provide a suitable platform for diagnoses like epilepsy to be discussed and normalised in schools. Engagement with outreach support groups may also offer the opportunity for those who find themselves isolated by their diagnosis to meet other children with epilepsy, fostering a sense of social unity [27].

Although some studies report that children can understand epilepsy-related concepts and issues [12], others have demonstrated that children struggle to describe their understanding of the diagnosis [43]. As children, our participants struggled to fully comprehend their diagnosis and its consequences. Children’s cognitive and linguistic skills can limit the extent to which they can participate in and comprehend complex social interactions with adults. Practitioners must therefore ensure that patient information for children is accessible and appropriate, and that the child’s understanding is acknowledged as central to the process of knowledge transfer [44,49]. Moreover, understandings of epilepsy may need to be revisited with children as they develop to ensure increasingly complex explanations of epilepsy match each child’s growing cognitive competencies. The understandings of parents may also need to be revisited as their knowledge, or lack thereof, may limit the extent to which they can assist their child in understanding epilepsy. Our participant’s misunderstanding when told that a child may ‘grow out’ of epilepsy is a salutary reminder to consider carefully how children may interpret information.

Irrespective of setting, those responsible for the treatment and care of children with epilepsy must be cognisant of acute emotional or environmental stress under which these children may be placed. As noted in the present study, seizure activity was perceived as a disruption to family functioning and a source of distress to parents and siblings, giving rise to significant feelings of guilt. Parents and teachers have been identified as central to positive youth development and outcomes [45]. These key adults require training and support to better understand the myriad of influences on these children’s psychosocial development, influences such as the cascading fear and perceived stigma reported by our

participants. Whether in clinic or the classroom, practitioners must also be aware of the family dynamics at play [46].

4.1. Strengths and limitations

As with all retrospective studies, the findings of present study may be subject to recall bias [47]. In addition, our participants' reflections may be influenced by factors such as treatment satisfaction and seizure status. As we previously noted, we accept that our participants' experiences were true to them, in the context of their upbringing. As participants were all raised in Ireland, our findings may reflect cohort effects, although as participants received their respective diagnoses across three decades, it may be argued that findings are not all attributable to time-specific social circumstances [48]. Despite these limitations, the interviews conducted in this study were comprehensive and yielded insightful data.

4.2. Future research

This study reports the retrospective experiences of Irish adults who experienced childhood epilepsy. Further research is required to determine whether these findings are replicated cross-culturally. Research is also needed to explore more specifically the various developmental trajectories deriving from childhood epilepsy.

5. Conclusion

The present study is the first, to our knowledge, to provide adults with the opportunity to reflect on their experiences of childhood epilepsy. With ample time having lapsed in order to process their experiences [48], and now boasting the linguistic competencies to accurately express them [44], participants' reflections generated three main themes which gave rise to a number of considerations for the treatment and care of young people with epilepsy across social, educational and clinical settings. The experience of emotions associated with loss or bereavement, the benefits of finding one's tribe, and recognition of the necessity for developmentally appropriate practice were commonly cited. In combination, these findings highlight the importance of person-centred supports that take cognisance of each child's capacity and context when navigating their diagnosis and lived experience of epilepsy. Information, resources and clinical engagement with children with epilepsy require the input of patients with current or past experience of childhood epilepsy to guide development. A co-production approach is needed to address some of the disenfranchised and isolating experiences recollected by our participants.

Declaration of Competing Interest

None.

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