Parents' experiences of caring for a child with epilepsy:

A systematic review of qualitative research and thematic synthesis

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Abstract

Purpose: Previous research highlights the impact of chronic health conditions on parents of children with health conditions, including epilepsy, however thus far there has not been a qualitative synthesis of the parental experience of caring for a child with epilepsy. This review aims to synthesise the available literature to gain greater insight into how parents experience their child's condition and to identify gaps in current healthcare provision. **Methods:** A systematic literature search of five electronic databases identified 14 papers which included data regarding the parental experience of caring for a child with epilepsy. A thematic analysis method was used to synthesise these papers. **Results:** Four main themes were identified: 1) prolonged uncertainty, 2) a 24-7 condition, 3) a multitude of losses and 4) facing societal stigma. **Conclusions:** The synthesis identified that parents face a range of experiences and emotions whilst caring for their child with epilepsy. Recommendations for how healthcare and third sector services can support parents further to help them cope with their experience are provided.

Key words: carers, healthcare professionals, seizure, stigma, uncertainty

According to the World Health Organization (2024), epilepsy is a chronic neurological condition that affects around 50 million people globally. It is characterised by having two or more unprovoked seizures. Such seizures can affect one or all parts of the body, and they may be accompanied by a loss of consciousness (World Health Organization, 2023). Epilepsy is thought to account for 1% of the global burden of disease (Murray et al., 2012) and the risk of premature death for those diagnosed with epilepsy is substantial (Murray et al., 2012).

Epilepsy affects people of all ages (Fiest et al., 2017), yet the challenges faced by children and adults with the condition may vary. Regardless of having epilepsy, childhood brings its own difficulties. Challenges include children's lack of experience to perceive problems accurately, lack of knowledge to handle challenging emotions, lack of choice in dealing with problems, and lack of logic when appraising a problem (Healy, 2018). In addition, children with epilepsy are significantly more likely to experience anxiety, depression, conduct problems, developmental delay and autism spectrum disorder than their peers (Russ et al., 2012). They may also experience educational and peer difficulties at school, poor social competence, greater parent aggravation, and be at increased risk of not having their medical and mental health needs met (Davies, Heyman & Goodman, 2003; Russ et al., 2012).

It is important to consider the impact of children's epilepsy on parents as research suggests that parental psychological difficulties can subsequently lead to a lack of attention to children's needs, negative parenting behaviours and increased family dysfunction within the home (Elgar et al, 2007; Wilson & Durbin, 2010). A systematic review and meta-analysis found that parents of children with a chronic illness experience higher levels of anxiety and depression than parents of unaffected children (Cohn et al., 2020). Parents of children with epilepsy may also experience feelings of uncertainty, stress, social isolation and financial burden (Duffy, 2011; Cushner-Weinstein et al., 2008; Nolan et al., 2006; Jones et al., 2019). As children may be dependent on their parents for some elements of epilepsy management, such as administration of medication, it is essential that parents are able to pay attention to their children's needs.

Furthermore, research shows that children of parents with mental health difficulties experience heightened levels of stress (Kamis, 2021) which is important to be aware of as acute stress can provoke seizures (dos Santos Lunardi et al., 2011; van Campen et al., 2012)

and chronic stress can increase seizure frequency (Kotwas et al., 2017). In addition to this, poor seizure control is more likely to predict mental health difficulties such as anxiety and depression (Schabert, 2022).

Currently there are no reviews of qualitative research that synthesise research findings on the parental experience of epilepsy. Such a review is important to understand the parental experiences of caring for a child with epilepsy, especially given the impact parental stress can have on the child. Qualitative research identifies values, beliefs and attitudes from individuals, which provides a deeper understanding of relationships and processes (Maxwell, 2013). Therefore, such a review will help to provide in depth insight into the parental experience of epilepsy and offer insights into gaps in care for both children with epilepsy and their family, thus allowing recommendations for further research and potential interventions to be made. Therefore, this study aims to systematically review and synthesise relevant qualitative research to determine the psychosocial impact of epilepsy from a parental perspective.

Method

This review was completed in line with Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) guidance (Moher et al., 2009) and the Enhancing Transparency in reporting the synthesis of qualitative research (ENTREQ) guidance (Tong et al, 2012). It was also registered in advance on PROSPERO (reference number: CRD42023479966).

Search Strategy

The research team devised a search strategy with support from a specialist subject librarian. A systematic search of five databases (Academic Search Ultimate, CINAHL, Medline, PsycArticles and PsycInfo) combined using EBSCO was completed in May 2024 (See Table 1 for search terms). The search terms were combined with Boolean operators ‘AND’ between concepts and ‘OR’ within concepts. The searches were limited to title and abstract only. Reference lists of included papers were also checked to identify any additional papers.

[INSERT TABLE 1 ABOUT HERE]

Eligibility Criteria

Eligible papers were those that: 1) were available as full texts; 2) were published in a peer reviewed journal; 3) were available in English; 4) described studies that utilised qualitative methods for data collection; 5) described studies that used an inductive qualitative methodology for data analysis; 6) presented studies based on first person parental experiences; 7) reported empirical studies whereby findings were evidenced by participant data; 8) were based on epileptic seizures and 9) were based on the psychosocial impact of epilepsy. Papers were excluded if they reported studies that were: 1) based on functional non-epileptic seizures; 2) focussed on the experience of other parts of the person's social support system (i.e. siblings, grandparents, teachers, healthcare professionals); or 3) a literature review.

Management of the Selection Process

All titles and abstracts were screened by the first author to check them against the eligibility criteria. After this screening process whereby the ineligible studies were removed, the first author then read the full texts of the remaining studies and completed the same screening process against the eligibility criteria (See Figure 1 for PRISMA Flow Diagram). To ensure reliability in the selection process, one independent reviewer reviewed 10% of titles and abstracts (=33) and 25% of full texts (n=4). The first author and independent reviewer were in full agreement therefore no disagreements needed to be resolved.

[INSERT FIGURE 1 ABOUT HERE]

Quality Appraisal

The quality of the included studies was assessed using the Critical Appraisal Skills Programme Qualitative Checklist (CASP; 2018) tool. This includes two screening questions to which the reviewer needs to answer 'yes' to be included, and eight items regarding study quality such as research design, data collection, and ethical issues. Each item had a three-point scoring system (see Duggleby et al., 2010), with a score of 1 representing weak evidence, a score of 2 representing moderate evidence, and a score of 3 representing strong evidence. All studies were quality assessed by the first author and 25% of studies (n=4) were quality assessed by an independent researcher. The scores for the included studies ranged from 18 to 24 (mean=20.9, SD=1.79) (See Table 2). Reviewers agreed on scores for two of four studies, and scores differed by one point for the remaining two studies. The discussion of

this difference was used to agree a consistent approach to scoring the areas of difference for all papers. The quality appraisal process was not used to exclude papers as it found that 12 of 14 studies were of high quality, and two studies were of moderate quality.

[INSERT TABLE 2 ABOUT HERE]

Data Extraction and Synthesis

The included data were analysed inductively using a thematic synthesis approach (Thomas & Harden, 2008). The data comprised all text containing author interpretations of primary data in the 'findings' or 'results' and 'discussion' sections of each paper. This included participant data excerpts and the authors' descriptions and interpretations of such data. The first author read each study multiple times, completing line-by-line coding whilst reading. This involved creating codes to capture the content and meanings of each sentence, progressing through the text of each primary study line by line. This process was completed for each included study. Next, the line-by-line codes that represented similar concepts were grouped together. Lastly, the first author analysed and interpreted the descriptive themes across papers to develop analytical themes. This involved 'going beyond' the original studies' content by using the produced descriptive themes to answer the initial review questions (Thomas & Harden, 2008). These themes were then examined and modified in discussion with the research team.

Study Characteristics

In total, 14 papers representing 14 separate studies were included in the synthesis (see Table 3). These papers were published between 2008 and 2022. Sample sizes ranged from 5 to 28 participants (mean=17.1). Nine studies totalled 139 parents and comprised of 108 mothers and 31 fathers. Four studies included 73 parents without specifying the number of mothers and fathers, and one study included 15 families, which also did not state the exact numbers of mothers and fathers. Studies were conducted in Australia, Canada, Denmark, Iran, Ireland, New Zealand, Norway, Taiwan, United Kingdom, and the United States of America.

Twelve papers utilised semi-structured interviews for data collection, one used focus groups (Berg et al., 2019) and another used both semi-structured interviews and focus groups (Lewis & Noyes, 2013). All papers used a qualitative approach with four studies using thematic analysis, four studies using grounded theory, three studies using interpretative

phenomenological analysis, one study used hermeneutic-phenomenological analysis, one study used Colaizzi's method and another used Giorgi's method. Inclusion of the above studies was agreed following discussion with a member of the research team with expertise in qualitative research (fourth author).

[INSERT TABLE 3 ABOUT HERE]

Results

Four themes were developed that reflected parents' experiences of caring for a child with epilepsy: 1) prolonged uncertainty, 2) a 24-7 condition, 3) a multitude of losses, and 4) facing societal stigma. Each theme (with subthemes) is presented below.

Theme 1: Prolonged uncertainty

Across the papers, parents expressed prolonged uncertainty regarding their child's epilepsy. This uncertainty occurred from the pre-diagnosis period where parents simply did not know why their child was presenting with certain behaviours, to post-diagnosis when parents did not know what the future held for their child and how the condition may change over time. Twelve papers contributed to this theme.

A common coping mechanism for parents was seeking information and education, principally from healthcare professionals who were deemed as 'experts of their child's condition' (Tschamper & Jacobsen, 2019, p.6; Harte et al., 2022; Nguyen, Pertini & Kettler, 2015). This process contributed to increasing parents' confidence and agency in supporting their child, with one mother stating that, "having information helped me feel more in control so I was more prepared if something was to happen" (Nguyen, Pertini & Kettler, 2015, p.32). However, on occasions parents found medical terminology and jargon to be a 'serious barrier to their engagement' which risked making them feel 'embarrassed' and 'angry' at healthcare professionals (Lewis & Noyes, 2013, p.16). Three subthemes regarding pre-diagnostic uncertainty, diagnostic uncertainty, and uncertainty for the future, are presented below.

Subtheme 1.1: Pre-diagnosis uncertainty

Several papers detailed a period before a formal diagnosis of epilepsy was made whereby parents did not know why their child was presenting with certain behaviours:

> For most families in this study, the onset of their child's epilepsy was met with confusion, misunderstanding and uncertainty. Identification of the children's epilepsy did not come easily for many of the participating families. Families described themselves as noticing the symptoms, but not understanding what they meant, particularly when the seizures were not stereotypical, such as absence seizures (Roberts & Whiting, 2011, p.170).

In one paper, 13 of the 15 families described not recognising their child's seizure as a seizure, and many concluded that their child's behaviour was 'just one of those things children do' as sometimes children do 'strange' things, daydream and play games which seizures were interpreted as (Webster, 2019, p.209).

When parents became concerned about their child's behaviour, they experienced a time of searching for answers before a diagnosis was made (Jeffrey et al., 2021) with some parents describing 'a long period of uncertainty waiting for a formal diagnosis' (Webster, 2019, p.210). As their child had not received a formal diagnosis, their symptoms were often untreated. For some parents there was a sense of 'relief' of finally receiving a 'label' and consequently knowing their child would receive treatment and being able to move forward without diagnostic uncertainty (Webster, 2019; Jeffrey et al., 2021).

Subtheme 1.2: Diagnostic uncertainty

Once parents had a label for their child's condition, which helped to alleviate uncertainty surrounding what was happening for their child, this stage in their journey introduced new uncertainties. Some parents described 'significant emotional upheaval subsequent to their child's diagnosis' (Nguyen, Pertini & Kettler., 2015, p.27).

Some parents still experienced prolonged uncertainty surrounding the diagnosis (Webster, 2019; Mu, 2008) and one mother stated:

> I have never had it explained to me, just that she has epilepsy. I don't even know what type she has now. I didn't realise that there were so many types. The only one I know is the one with lights (Lewis & Noyes, 2013, p.16).

Some parents described experiencing motivation to 'exploit all potential sources of information' to know more about their child's diagnosis and manage their seizures. A key coping mechanism for parents experiencing uncertainty about their child's epilepsy was information-seeking, with some parents describing 'self-empowerment' by learning from professionals, books and others' lived experiences, and gaining an increased sense of control (Bagherian, Nematollahi & Mehdipour-Rabori, 2021; Nguyen, Pertini & Kettler, 2015).

Subtheme 1.3: Uncertainty for the future

After receiving an epilepsy diagnosis for their child, some parents described feeling alone and likened the experience to taking home and looking after a newborn baby (Webster, 2019), alluding to the uncertainty and unfamiliarity related to such an experience. Parents expressed uncertainty regarding what the future held for them including: fears around potential brain damage, sudden unexplained death in epilepsy, whether the condition would worsen during puberty, the impact on their child's prospects and whether they would grow out of it (Mu, 2008; Berg et al., 2019; Webster, 2019; Lewis & Noyes, 2013). Some parents were able to maintain hope for positive outcomes during this time (Nguyen, Pertini & Kettler, 2015; Jeffrey et al., 2021), whereas others were described to 'fear the worst' (Lewis & Noyes, 2013, p.20). For some parents, concerns were expressed regarding when their child would become an adult, when they would no longer be attached to a paediatric department, and parents were worried they would not be properly supported (Roberts & Whiting, 2011).

Theme 2: A 24-7 condition

Parents often alluded to epilepsy being a condition that consumed their life 24 hours a day, 7 days a week and 52 weeks a year. Aside from caring for their child during a seizure, parents reported spending their time between seizures in a state of hypervigilance, anticipating the next seizure and with a heightened awareness of risk. One father encapsulated this experience: "It's just like you are tense, and you cannot relax at all. Just like waiting for a war, very nervous" (Mu, 2008, p.547). Three subthemes were developed relating to hypervigilance, a heightened risk of awareness and inter-seizure anticipation, with eight papers contributing to the overall theme.

Subtheme 2.1: Hypervigilance

Parents changed their lifestyle at the onset or diagnosis of their child's epilepsy (Mu, 2008). Part of this adaptation was the 'constant surveillance' and monitoring they felt was required to keep their child safe (Lewis & Noyes, 2013). Such monitoring and surveillance included keeping track of seizures, keeping diaries of 'unusual behaviours', changing their sleeping arrangements to monitor their child overnight, constantly checking out potential risks to their child and buying safety products such as monitoring devices (Berg et al., 2019; Webster, 2019; Cook et al., 2023; Bagherian, Nematollahi & Mehdipour-Rabori, 2021). Some parents perceived their newfound hypervigilance and monitoring as a means of providing reassurance to their children (Cook et al., 2023). However, others felt that they "function in 'crisis mode' throughout everyday" (Berg et al., 2019, p.298).

As a result of their constant monitoring, some parents experienced burnout due to feeling burdened, physically exhausted, lacking time for self-care and sleep deprivation (Bagherian, Nematollahi & Mehdipour-Rabori, 2021; Mu, 2008; Nguyen, Pertini & Kettler, 2015; Berg et al., 2019). Several parents recognised the need to look after their own wellbeing to care for their child and one commented that upon engaging more in self-care activities, they were re-energised to continue their carer role: "I need to do things for myself and if I don't I'm not good to anyone else" (Nguyen, Pertini & Kettler, 2015, p.32).

Subtheme 2.2: Heightened risk awareness

One element of parents' hypervigilance was a heightened awareness of risk to their child with epilepsy compared to peers without the condition; one paper referred to this as conceptualising risk through an 'epilepsy lens' (Webster, 2020). Parents felt that most settings and activities now posed a greater risk to their child with epilepsy including swimming, heights and crossing the road (Webster, 2020). As a result, parents would often check out risks more than they used to, stay 1:1 with their child and/or restrict the activities their child engaged in (Bagherian, Nematollahi & Mehdipour-Rabori, 2021; Webster, 2020; Lewis & Noyes, 2013). Parents felt this was keeping their child safe, however one parent was aware of her child being unhappy when they held her hand by the roadside, and others felt they were invading their child's privacy. The parents' heightened risk awareness was complicated by the unpredictability of seizures and the fact that seizure onset might have no visible warning signs (Webster, 2020). Although this consumed a lot of parents' time by constantly looking out for risk, it was suggested that perceptions of risk are higher at

onset/diagnosis (Webster, 2020) and epilepsy was less of an ordeal over time and experience of living with the condition (Nguyen, Pertini & Kettler, 2015).

Subtheme 2.3: Inter-seizure anticipation

Several parents spent a large amount of time and energy anticipating their child's next seizure and lived in "constant dread of the next seizure" (Berg et al., 2019, p.298). One paper described this as a "24-7-52 pending crisis" (Berg et al., 2019, p.295) indicating that parents know a seizure will happen at some point and are constantly waiting for it to occur. They felt a loss of control which was an intense stressor for them and something that they had to come to terms with over time: "I'm still aware of the unpredictability of it but I kind of understand it more in that there are certain aspects I have no control" (Nguyen, Pertini & Kettler, 2015, p.29). They also felt that it was hard to make plans during the inter-seizure period due to the unpredictability of seizures and worried that a seizure might happen at any time (Berg et al., 2019).

Theme 3: A multitude of losses

Parents expressed numerous negative emotions surrounding their child's diagnosis of epilepsy including guilt, despair, shock and anger (Mu, 2008). One parent described the 'grief' they felt at the diagnosis (Nguyen et al., 2015, p.31) and another described the experience as a 'trauma' (Jeffrey et al., 2021, p.154). Many expressed difficulties accepting their new reality (Bagherian, Nematollahi & Mehdipour-Rabori, 2021) and experienced loss in numerous ways. A total of eight papers contributed to the overall theme. Three subthemes are presented: the loss of a 'healthy' child, a loss of their imagined future, and a change in parents' identities.

Subtheme 3.1: Loss of a 'healthy child'

Parents expressed the experience of 'loss' of their previously healthy child (Lewis & Noyes, 2013) or feelings of an 'impending' loss of their healthy child (Mu, 2008). In one paper most parents struggled to make sense of their situation stating that "they could not understand why their healthy normal child suddenly developed epilepsy" (Lewis & Noyes, 2013, p.16). The loss of their child's previous 'healthy' status seemed to be difficult for parents to comprehend and witness, with one parent alluding to wishing it was them, not their child: "I told God, what you do my God, what did you get from this kid? On the night of

winter, I swore allegiance to God. I said, if I'm guilty why my child. You have to punish me" (Bagherian, Nematollahi & Mehdipour-Rabori, 2021, p.333).

Parents reported managing these feelings of losing their 'healthy' child by drawing comparisons to less fortunate people, and with more aggressive and debilitating conditions: "I rationalize and think well he could have a million other terrible things", and drew comparisons between other easier to manage types of epilepsy, for example those whose children experienced absence seizures would compare them to children who had tonic-clonic seizures (Nguyen, Pertini & Kettler, 2015, p.28). This cognitive reappraisal appeared to help parents rationalise and shift their perspectives.

Subtheme 3.2: Loss of imagined future

Parents also alluded to a loss of their previously imagined future prior to their child's diagnosis of epilepsy. Several parents questioned whether their child's imagined future might be cut short for fear of Sudden Unexplained Death in Epilepsy (SUDEP) (Lewis & Noes, 2013; Webster, 2020), and others described how the diagnosis "destroyed earlier dreams of a bright future" (Mu, 2008, p.548) including concerns around their child's education, job prospects, and independent living (Webster, 2019). Parents also expressed grief for what might have been for themselves. For some parents of children with a genetic form of epilepsy, they expressed a fear of passing the condition on to future children and despite their desire to have more children they decided not to (Jeffrey et al., 2021).

Parents adjusted in a similar way by reappraising the situation. They described revising their interpretations of what constitutes 'quality of life' by frequently restructuring their expectations to make 'good days' more attainable, setting more realistic bars of achievement and happiness, and abandoning their previous expectations inherent with healthy children (Nguyen, Pertini & Kettler, 2015).

Subtheme 3.3: Changes in parents' identities

Parents reported losing parts of their identity separate to being a parent. For example, several parents explained having to give up their career to provide the best care for their child:

> "I had to resign from my work because of my son's epilepsy and to care for him, so that I am his full-time carer. We would have done anything. At one stage we thought

we would even consider going overseas to access cannabis if that was the way we had to do it" (Harte et al., 2022)

Parents also reported reduced engagement in activities that they previously enjoyed and some experienced marital stress because of their caring responsibilities for their child (Berg et al., 2019). However, some parents adjusted to and reached acceptance of the limitations placed on them when parenting a child with epilepsy and over time were able to return to activities they previously enjoyed (Bagherian, Nematollahi & Mehdipour-Rabori, 2021; Nguyen, Pertini & Kettler, 2015). Some parents experienced personal growth from their experiences and found being able to offer help and advice to others based on their own lived experience of epilepsy rewarding (Nguye, Pertini & Kettler, 2015). This revised part of their identity seemed to be a significant coping mechanism for them.

Theme 4: Facing societal stigma

Nine papers highlighted the impact of stigma surrounding epilepsy. Such stigma was experienced by parents as coming from external sources, but parents also reported internalising stigmatising beliefs (Webster, 2020) and had negative implications for both children and their parents, whilst increasing feelings of irritation towards others (Amjad, Nasrabadi & Navab, 2017). Furthermore, cross-cultural differences in the extent and type of stigma were evident. Two subthemes are presented which discuss the impact of stigma and unhelpful responses from others, and the cultural stigma some families faced.

Subtheme 4.1: The impact of stigma and unhelpful responses from others

Parents noted a lack of societal knowledge and understanding of epilepsy (Amjad, Nasrabadi & Navab, 2017). They were aware of public perceptions and judgements about their child, observed unhelpful responses from others, and heard negative comments about their child which led to feelings of irritation towards others (Jeffrey et al., 2021; Webster, 2020; Amjad, Nasrabadi & Navab, 2017). Some parents noted stigma around their child's future including relationships and marriage (Amjad, Nasrabadi & Navab, 2017). They felt they needed to educate others due to the lack of knowledge (Berg et al., 2019) and they experienced limited social support due to others not truly understanding their situation (Nguyen, Pertini & Kettler, 2015). They often described feeling isolated and unsupported (Berg et al., 2019), however communicating and relating to other parents of a child with

epilepsy was experienced as supportive and reduced feelings of isolation (Jeffrey et al., 2021).

Subtheme 4.2: Cultural stigma

Parents' experiences of stigma varied across cultural contexts. Studies conducted in Taiwan and Iran highlighted stigma around the cause of epilepsy with some families blaming God, and others indicating that the condition was a punishment (Bagherian, Nematollahi & Mehdipour-Rabori, 2021). Some parents perceived others as thinking the condition was contagious: "They looked at us as if our child has AIDS" (Amjad, Nasrabadi & Navab, 2017, p.62). Others experienced people considering their child's condition 'an unacceptable illness' (Mu, 2008), with societal narratives of their child being a 'sick child' (Amjad, Nasrabadi & Navab, 2017).

Such societal narratives lead to wider families or relatives visiting the child less and maintaining physical distance from them (Amjad, Nasrabadi & Navab, 2017) which parents found shocking. Some parents were perceived as being to blame for their child's condition thus experiencing verbal abuse (Amjad, Nasrabadi & Navab, 2017), and many others experienced 'familial shame' (Mu, 2008). Due to a fear of being ridiculed and unaccepted by society, some parents decided to conceal and hide their child's epilepsy by keeping it a 'secret' and avoided discussing it outside of the family home to avoid damaging their social image (Mu, 2008; Amjad, Nasrabadi & Navab, 2017). Due to the negative social connotations of the condition, many parents experienced shock, anger, despair and guilt (Mu, 2008).

Discussion

This systematic literature review aimed to synthesise qualitative research findings about parents' experiences of caring for a child with epilepsy. The review identified four themes that encapsulated parents' experiences including: parents living with many uncertainties throughout their child's journey with epilepsy (theme 1), experiencing a heightened awareness of risk to their children (theme 2), experiencing multiple losses after their child's condition (theme 3), and being subject to societal stigma particularly in non-western cultures (theme 4).

The synthesis identified that parents experienced strong emotions following their child's diagnosis of epilepsy that are commonly associated with loss and grief, including

shock, anger, despair and guilt. Parents experienced the profound loss of a healthy child, expressed a desire to change places with them, and sometimes felt their child's epilepsy was a punishment for a personal failing of their own. They also recounted grief for a lost possible future, for both them and their child. Considering the Kubler-Ross and Kessler (2005) grief cycle, some parents appeared to go through the natural process of grief for their child's diagnosis before reaching eventual acceptance over time. This accords with previous research outlining that parents of children with chronic illnesses often experience grief, which can be most intense at the point of diagnosis (George et al., 2007). This is useful to consider given that one systematic review found that mindfulness and acceptance interventions are beneficial for parents of children with chronic health conditions (Ruskin et al., 2021), suggesting that this could be a helpful intervention to support those who may be experiencing grief and struggling to reach acceptance.

The review also highlighted that parents often sought information and reassurance from healthcare professionals following their child's diagnosis. The information was received sometimes positively and regarded as helpful, and at other times it was perceived to be confusing and unhelpful. This aligns with previous research highlighting that parents sometimes struggle with the use of medical jargon and overload of information, leaving them confused and frightened because they could not resolve anxieties that confronted them at the time (Hummelinck & Pollock, 2006). These communication issues risk compromising an effective relationship between parents and healthcare professionals (Hummelinck & Pollock, 2006).

The synthesis also highlighted cultural differences in the parental experience of caring for a child with epilepsy, particularly highlighting the shame some parents faced in their communities and cultures, with some resorting to concealing their child's condition. This is important to consider given quantitative research has found that concealment of a child's health condition predicted children's psychosocial, emotional and peer socialisation difficulties, with the research suggesting that families should be supported in decision-making when considering concealing their child's condition (Hackford, 2020).

Furthermore, the review highlighted that some parents cope with their child's diagnosis of epilepsy by cognitively reappraising the situation, comparing their child's health with what they deem as more severe or dangerous conditions or types of epilepsy. This can be understood through Lazarus and Folkman's (1987) transactional model of stress and

coping whereby individuals cope with stressful situations in three steps: primary appraisal, secondary appraisal and utilising coping strategies. These stages involve assessing how the event will affect their wellbeing, evaluating whether they have the resources available to cope with it, and employing problem-focused or emotion-focused coping strategies. It is useful to consider the coping mechanisms which may help parents manage stress given the long-term effects of stress on the nervous system (Reznikov et al., 2007), physical health conditions (Yaribeygi et al., 2017) and mental health difficulties (Marin et al., 2011), and the impact of parental stress on child outcomes such as behavioural difficulties (Neece, Green & Baker, 2012).

Implications for health and third sector practice

As previously mentioned, the review found that many parents seek information from healthcare professionals who are their first point of contact, seeing them as 'experts' on their child's condition and such information alleviated some of the uncertainties they experienced. Typically, the process of seeking information was helpful and empowering, however some parents commented on the jargon used making them feel confused and embarrassed for not understanding. As this could be damaging to the relationship between parents and the healthcare professionals (HCPs) responsible for their child's care, targeted advice and training around tailoring communication to the parents' needs would help these HCPs. Furthermore, the review found that parents experience different types of uncertainties at different points of their journey such as uncertainty around the cause of their child's epilepsy pre-diagnosis, and concern about their future. Support for HCPs to offer basic psychological interventions at this point, such as psychoeducation, may be helpful, however support for them to recognise when parents need signposting to additional support, such as a referral to psychologists, would also be needed.

In addition to the role of healthcare professionals, the work of third sector organisations (such as Epilepsy Action in the UK) means that they are well placed to provide an important complementary source of information and support for parents seeking to understand their child's condition. These organisations can help to ensure that parents receive accurate, accessible, and jargon-free information through clearly written resources, online webinars, or parent-friendly videos. Collaboration between healthcare services and third sector organisations could help ensure that information provided to families is consistent and

evidence-based, helping to reduce confusion and anxiety during what is often an overwhelming time.

Many parents reported experiencing multiple losses due to their child's diagnosis of epilepsy and expressed a range of emotions like those stated in the Kubler-Ross and Kessler (2005) grief cycle. This echoes research that found that parents of children with chronic illnesses experienced grief in relation to their child's health, with the initial diagnosis being the most stressful part of the grieving process (George et al., 2007). As parents may experience loss and grieve for such losses, they may benefit from direct psychological input to help process this and move forward. Also, given the impact a diagnosis has on families, healthcare professionals who deliver diagnoses may benefit from training or consultation (e.g., from clinical psychologists) to deliver the diagnosis in the most sensitive way. The findings of the current review suggests that parents are sometimes uncertain about their child's type of epilepsy and the outlook for the condition at the point of diagnosis, therefore they may benefit from clearer information tailored to their needs and delivered in a sensitive way.

Third sector organisations could play a valuable role in supporting parents through this period of adjustment by facilitating peer-led support groups or online communities that allow parents to connect with others who have shared similar experiences. Such groups can normalise feelings of grief, guilt, and anxiety, helping parents to feel less isolated and more understood. These organisations may also be well placed to co-develop psychoeducational workshops or online resources informed by Compassion Focused Therapy (Gilbert, 2009) or acceptance-based approaches, helping parents to manage feelings of guilt, shame, and self-criticism that often accompany the caregiving role.

Additionally, the review highlighted the stigma that some parents experience, particularly amongst non-western populations. The development of psychoeducational resources, such as accessible leaflets and websites, may be beneficial to provide information about the known causes of epilepsy to help break such stigma. Given the impact stigma can have on parents, healthcare professionals who deliver the diagnosis of epilepsy may benefit from training about how to diagnose the condition sensitively with respect for the parents' cultural beliefs. Third sector organisations are also well positioned to lead community-based initiatives aimed at reducing stigma. Working in partnership with cultural and faith community leaders, they could deliver awareness campaigns, provide translated resources,

and train parent ambassadors from diverse backgrounds to act as trusted voices within their communities. These efforts could help to challenge misconceptions about epilepsy and promote understanding and inclusion.

Furthermore, given the shame and guilt that parents reported experiencing in this review, they may benefit from interventions designed to cultivate self-compassion and reduce the influence of the threat system (associated with fear, shame, and self-criticism) and the drive system (associated with over striving and the pursuit of self-worth through achievement) in their lives. Both healthcare services and third sector organisations could embed compassion-based principles within their support approaches to promote warmth, validation, and a sense of safeness in interactions with families.

Finally, many parents stated that peer support from other parents with a child with epilepsy was normalising, reassuring, and reduced feelings of isolation and alienation. Health services may be able to bring people together and offer peer support groups, and psychologists may have a role in facilitating such groups to offer psychoeducation, normalisation, and validation, as these factors are key for positive therapeutic outcomes (Yuen et al., 2022). Collaboration between healthcare providers and third sector organisations could further strengthen this provision, ensuring that support is both clinically informed and accessible within community settings. By combining clinical expertise with community-based compassion and advocacy, these organisations can play a vital role in helping parents navigate the emotional, social, and practical challenges of raising a child with epilepsy.

Strengths and limitations

This systematic review synthesised qualitative findings regarding parents' experiences of caring for a child with epilepsy. The inclusion of studies conducted across many countries and cultures mean the findings have greater applicability to a wider population (although some findings, such as those related to cultural stigma, may be specific to particular social groups and geographical regions). A limitation of the review is the subjectivity which is inevitable in qualitative literature synthesis. The authors select, appraise and synthesises findings from studies which risks bias within the results. However, the authors made efforts to ensure rigour as an independent researcher took part in the selection and quality appraisal process. Furthermore, the first author completed codes and identification of themes, however final themes were collaboratively discussed with the wider research team. Additionally, the ENTREQ guidelines (Tong et al., 2012) were followed to ensure the stages associated with

the synthesis of qualitative health research were reported. Lastly, most participants were mothers therefore the findings contain more of the mothers' perspectives than fathers'. This may be due to the influence of societal gender roles on the reasons for less fathers taking part in the research; however, it is important to gain insight from them as their experiences may differ from mothers.

Future research

This systematic review provided insight into parents' qualitative experiences of caring for a child with epilepsy. Some papers briefly mentioned the impact of epilepsy on the wider family, including siblings, but overall, there is a significant lack of research into the impact on siblings. Future research should aim to address this gap to inform healthcare service's understanding of the impact of epilepsy on the wider family system around the child to establish whether there may be a need for emotional support for siblings.

Furthermore, the review highlighted that some parents coped by appraising their situation in comparison to those with different or more severe types of epilepsy. Future research could explore and compare how parents may cope differently with a variety of seizures included absence seizures, myoclonic seizures and tonic-clonic seizures. This insight may inform healthcare services to offer person-centred support tailored to the differing needs of parents based on their child's type or severity of epilepsy.

Moreover, there is a lack of research regarding fathers' parental experiences of caring for a child with epilepsy. It is important for future research to address this gap given the traditional gender roles within society and the stigma men face regarding their mental health. Men may be less able to take part in such research for a variety of reasons including the stigma around expressing their emotions (McKenzie et al., 2022), so future research should consider the most effective way of recruiting and engaging men in such studies.

Conclusion

Parents experience a range of emotions throughout their child's journey with epilepsy. This review highlight that parents face significant uncertainties regarding their child's epilepsy and they experience loss in many ways including loss of their healthy child and a loss of the future they envisioned for themselves and their child. Societal narratives and stigma surrounding an epilepsy diagnosis were shown to influence their experiences, and both consistencies and variability across global regions and cultures were highlighted. This

review demonstrates the role of health professionals in supporting parents of children with epilepsy, and for communication training for HCP's.

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Tables and Figures

Table 1. Database Search Terms

Search String
(MH "Epilepsy, Generalized") OR (MH "Epilepsy") OR (MH "Epilepsy, Absence") OR (MH "Epilepsy, Partial") OR (MH "Epilepsy, Partial, Complex") OR (MH "Epilepsy, Temporal Lobe") OR (MH "Epilepsy, Partial, Focal") OR (MH "Epilepsy, Juvenile Myoclonic") OR (MH "Epilepsies, Myoclonic") AND TI ((MH "Biological Parents") OR (MH "Adoptive Parents") OR (MH "Mothers") OR (MH "Fathers") OR (MH "Caregivers") OR (MH "Parents") AND "experience" OR (MH "Coping") OR "adjustment" OR "processing" OR "risk" OR (MH "Stigma") OR "social" OR "adapt" OR (MH "Stress") OR (MH "Quality of Life") OR (MH "Psychological Well-Being") OR "wellbeing" OR (MH "Caregiver Burden") OR "burden" OR (MH "Uncertainty") OR (MH "Worry") OR “perspective” AND (MH "Qualitative Studies") OR (MH "Ethnographic Research") OR (MH "Grounded Theory") OR (MH "Interviews") OR (MH "Focus Groups") OR (MH "Case Studies") OR "interpretative phenomenological analysis" OR (MH "Discourse Analysis") OR "narrative" OR (MH "Thematic Analysis") OR (MH "Content Analysis")

TABLE 2. CASP Rating Scores

Author (Year)	Appropriate design	Appropriate recruitment strategy	Appropriate data collection	Researcher-participant relationship	Ethical considerations	Rigour of data analysis	Clear statement of findings	Valuable research	Total (Duggleby et al., 2010)
Roberts & Whiting (2011)	3	2	3	1	2	3	3	2	19
Webster (2020)	3	2	3	1	3	2	2	2	18
Nabi Amjad, Nikbakht Nasrabadi & Navab (2017)	3	3	3	1	3	2	2	3	20
Bagherian, Nematollahi & Mehdipour-Rabori (2021)	3	3	3	3	3	3	2	2	22
Cook et al., (2023)	2	3	3	3	1	3	3	3	21
Nguyen, Pertini & Kettler (2015)	2	3	3	1	2	3	3	3	20
Harte et al., (2022)	2	3	3	1	2	3	3	3	20

Tschamper & Jakobsen (2019)	3	3	3	3	3	3	3	2	23
Mu (2008)	3	3	3	2	3	3	3	3	23
Jeffrey et al (2020)	3	3	3	2	3	3	3	2	22
Lindhart et al (2021)	3	3	3	2	3	3	3	2	22
Berg et al (2019)	2	3	3	1	2	3	1	3	18
Webster (2019)	3	3	3	1	3	3	3	2	21
Lewis & Noyes (2013)	3	3	3	3	3	3	3	3	24

The scores were rated following the criteria specified by Duggleby et al (2010). 1 point was assigned to studies that offer little or no explanation for a particular issue, 2 points was assigned to studies that addressed issues but did not provide elaboration, and a score of 3 points was assigned to studies that offered extensive justification of the issue at hand. Based on this, studies were given an overall rating of being low quality (score of 1-8), moderate quality (score of 9-18) and high quality (score of 19-24).

Table 3. Characteristics of papers included in the analysis

Title	Author(s) and year	Research aim(s)	Participants	Data collection method	Type of analysis	Relevant themes
Cannabidiol and refractory epilepsy: parental and caregiver perspectives of participation in a compassionate access scheme	Harte et al (2022)	To understand families expectations and attitudes about the use of an investigational cannabinoid product for their child's seizures To understand families' perceptions of Cannabidiol's efficacy for their child's seizures; and other aspects of their child's behaviour, quality of life and/or cognition	23 parents	Semi-structured interviews	Thematic analysis	Social engagement Clinical support Social acceptance of drug therapy
Childhood epilepsy in contemporary society: risk perceptions among children and their family members	Webster (2020)	To explore family members perceptions of the risks associated with epilepsy	28 parents	Semi-structured interviews	Grounded theory	Reconceptualised physical risks when viewed through an 'epilepsy lens' Stigma and difference
Developmental and epileptic encephalopathy: Personal utility of a genetic diagnosis for families	Jeffrey et al (2020)	To explore the additional personal utility of receiving a genetic diagnosis for families	15 families	Semi-structured interviews	IPA	Importance of the label Relief to end the diagnostic journey

Family stigma associated with epilepsy: a qualitative study	Nabi et al (2017)	To understand the experiences of parents' of child with epilepsy in Iran	6 mothers 4 fathers	Semi-structured interviews	IPA	Family stigma
Seizure burden in severe early-life epilepsy: Perspectives from parents	Berg et al (2019)	To characterise the multi-faceted nature of seizure burden in young people and their parents who are living with severe early-life epilepsies	10 parents	Focus group	Grounded theory	Seizure burden Educating others to provide appropriate care for child Impact on caregiver 24-7-52 Future Financial Social reactions of others
How parents cope with the care of a child with epilepsy: based upon grounded theory.	Bagherian et al (2021)	To explore the adaptation process in parents of children with epilepsy	15 mothers 5 fathers	Semi-structured interviews	Grounded theory	Denial of the child's illness Escape from reality Looking for guilt Caring patiently Imposing the pressure of the situation on oneself Changing the life routine Self-empowerment of the parents
Parents' experiences of videoconference as a tool for multidisciplinary information exchange for children with epilepsy and disability	Tschamper & Jakobsen (2019)	To explore the parents' experiences with the multidisciplinary information exchange between different levels of the health, social and school services using video conference	4 mothers 1 father	Semi-structured interviews	Hermeneutic–phenomenological analysis	To feel responsible Trust as prerequisite

The cycle of uncertainty: parents' experiences of childhood epilepsy	Webster (2019)	To explore parents experiences of uncertainty resulting from having a child with epilepsy	23 mothers 4 fathers	Semi-structured interviews	Grounded theory	Diagnostic uncertainty The cycle of uncertainty Uncertain futures
'No one's ever said anything about sleep': A qualitative investigation into mothers' experiences of sleep in children with epilepsy	Cook et al (2023)	To explore the types of parentally reported sleep problems faced by children with epilepsy and their families To identify parents experiences and feelings around managing their childs sleep and any associated problems To identify parents perception of available help and support when parenting a child with epilepsy around sleep	9 mothers	Semi-structured interviews	Thematic analysis	Longstanding challenging nature of child sleep issues Co-sleeping Challenges related to managing sleep over time Maternal anxiety around night-time seizures Lack of information, help and support available
Parental cognitive appraisals and coping behaviours following child's epilepsy diagnosis: A qualitative study	Nguyen, Pertini & Kettler (2015)	To investigate parental narratives and experiences in the aftermath of an epilepsy diagnosis	21 mothers	Semi-structured interviews	Thematic analysis	Adjustment process Cognitive appraisals Coping behaviours
Effective process or dangerous precipice: qualitative comparative embedded case study with young people with	Lewis & Noyes (2013)	To explore communication, information needs and experiences of knowledge exchange in clinical settings by young people and their parents during transition from children's to adult epilepsy services	28 parents	Qualitative comparative embedded case study – interviews and focus groups	Thematic analysis and pattern matching	Disengaging from healthcare Communication barriers Clarity

epilepsy and their parents during transition from children's to adult services						
Transition experience of parents caring of children with epilepsy: A phenomenological study	Mu (2008)	To investigate the essence of the family health-illness transition experience from the parental perspective when a child is afflicted with epilepsy	10 couples	Semi-structured interview	Colaizzi's method	Parental psychological reactions Parental coping patterns Family resources
The personalised discharge letter: the experience of patients and parents from the Filadelfia Epilepsy Hospital	Lindhart et al (2021)	To examine the experience of a discharge letter received by patients suffering from epilepsy and parents with children who suffer from epilepsy	5 mothers	Semi-structured interviews	Giorgi's method	A sense of feeling secure
Caregivers of school children with epilepsy: findings of a phenomenological study	Roberts & Whiting (2011)	To identify the perceptions and experiences of the primary caregivers of young children with epilepsy regarding their interaction with the schools which impact both the child's and family's quality of life, and to clarify how families think schools can best support, accommodate and prepare for these children and families.	7 caregivers	Semi-structured interviews	Phenomenological methods	Uncertainty at epilepsy onset, false interpretations of epilepsy by others, uncertainty about prognosis, importance of maintaining hope

Figure 1. PRISMA Flow Diagram