



Review

Families' experiences of living with pediatric epilepsy: A qualitative systematic review



Jeni Harden^{a,b,*}, Rebecca Black^{b,c}, Richard F.M. Chin^{b,c}

^a Usher Institute for Population Health Sciences and Informatics, University of Edinburgh, Teviot Place, EH8 9LG, UK

^b Muir Maxwell Epilepsy Centre, University of Edinburgh, Sylvan Place, EH9 1UW, UK

^c Child Life and Health, University of Edinburgh, Sylvan Place, EH9 1UW, UK

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ABSTRACT

Living with epilepsy in childhood has implications for the child and their family beyond the physical effects associated with epileptic seizures. Qualitative research has emerged, aiming to deliver a greater depth of understanding of the experiences of living with epilepsy from the perspectives of children with epilepsy, their parents, and their siblings. This review of qualitative research had three aims: first, to synthesize the demographic and epilepsy profiles of research participants in eligible studies in order to provide a clear picture of who are included and excluded when studying families' experiences; second, to present and discuss the methodological concerns and implications of research involving children with epilepsy; and third, to synthesize the findings arising from qualitative research with families in order to identify common themes across all relevant studies to date.

Papers published in the English language prior to January 2016 were identified following a search of eight electronic databases: Embase, Psycinfo, Medline, CINAHL, Web of Knowledge, ASSIA, Web of Science, and SCOPUS. Studies were included if they involved a sample of children with epilepsy (up to 18 years of age), parents, or siblings of children with epilepsy and used qualitative methods. Twenty-one studies were identified as eligible for inclusion in the review.

Findings in relation to the three aims were the following: 1) Researchers were seeking an understanding of children's experiences directly from children rather than by parental proxy. However, children with learning disabilities were often excluded from research, meaning that their views are not being heard. Parental research was predominantly with mothers, and father experiences were not often accessed. There was very little research with siblings. 2) The rationale for and ethical implications of the choice of research methods adopted were not always clear, and not all studies gave adequate attention to the development of appropriate methods for research involving children. 3) Two dominant themes emerged across the studies: normalcy and children's agency. Cutting across many of the challenges that living with epilepsy presented was the desire (by parents and children) for a 'normal' childhood. The studies also highlighted that children have knowledge about their own condition and epilepsy more generally and that they are involved in managing the ways in which they cope with epilepsy, both in terms of seizure prevention and managing their relations with others, particularly peers.

Future research should ensure that appropriate design, data collection, and analytic strategies are adopted to facilitate the participation of all family members. Enhancing the quality of the research will, in turn, optimize validity and opportunities for the translation of findings into better health, education, and social practices to improve care for children and their families affected by epilepsy.

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1. Introduction

Living with epilepsy in childhood has implications for the child and their family beyond the physical effects associated with epileptic seizures [1,2]. Utilizing quality-of-life (QoL) measures, research has

demonstrated a detrimental effect on academic achievement, associated with poor behavior management and performance, social isolation, and low self-esteem for children with the condition [3,4]. Parents of children with epilepsy have also been shown, using similar tools, to have higher rates of depression, anxiety, and stress because of the additional burdens and care needs associated with having a child with a chronic illness [2,3].

However, questions have been raised as to whether a quantitative approach can fully capture children's and parents' experiences of living with epilepsy [5,6]. Moreover, children's own views of their epilepsy have often been overlooked in favor of obtaining proxy assessments

* Corresponding author at: Usher Institute for Population Health Sciences and Informatics, University of Edinburgh, Teviot Place, EH8 9LG, UK. Tel.: +44 131 650 6991. E-mail address: jeni.harden@ed.ac.uk (J. Harden).

generated by the use of quantitative tools with parents [7–9]. In response, qualitatively led research on the topic has emerged, aiming both to deliver a greater depth of understanding of the experiences of children and their parents and, subsequently, to improve the care provided to these families.

Previous reviews of the qualitative research on this topic [5,10] have applied a QoL lens to the literature, providing insight into how the key QoL domains are affected by pediatric epilepsy. However, a focus on QoL may limit inclusion of relevant literature that has not adopted this approach. In addition, existing reviews, while addressing some issues pertaining to the quality of the research being reviewed, have not presented a detailed analysis and discussion of the research methods used. In this systematic review, we synthesized the findings and methods from all available qualitative research on experiences of living with epilepsy from the perspective of children with epilepsy (cwe), siblings, and parents.

The review had three aims relating to research participants, research methods, and research findings. First, it synthesized the demographic and epilepsy profiles of research participants in eligible studies in order to provide a clear picture of who the studies included and excluded. Second, the review synthesized all findings arising from qualitative research with children, parents, and siblings in order to identify common themes across all relevant studies to date. Third, using standard qualitative research quality criteria and assessment of appropriateness regarding researching with children, this review assesses the methodological approaches and implications of research involving children with epilepsy. By addressing these aims, the review embraced a holistic review of research with cwe and their families which facilitates further understanding of both the findings of research and the manner in which these findings are established.

2. Methods

2.1. Search strategy and study selection criteria

The literature search for the review was conducted between March and December 2014, and then, the same searches were run again January to February 2016.¹ The team held initial discussions to develop the MeSH (Medical Subject Heading) search terms, based on the SPIDER (Sample, Phenomenon of Interest, Design, Evaluation, Research type) search tool [11] which is specifically designed for qualitative evidence synthesis. We searched the Cochrane Database of systematic reviews, Embase, Psycinfo, Medline, CINAHL, Web of Knowledge, ASSIA, Web of Science, and SCOPUS. Details of the search terms and the combination of searches used are given in Table 1. The inclusion and exclusion criteria for the review related to date, language, study design, population, and study focus (Table 2).

2.2. Methods of the review

The screening process involved several stages (see Fig. 1). First, the databases were searched and duplicates removed. The titles of the papers were reviewed by JH, and where the focus was not clear in the title, the abstract was examined. Those considered relevant based on specific mention of pediatric epilepsy or epilepsy and families in the title or abstract were included. The abstracts of the remaining 160 sources were examined by JH. When the abstract was not descriptive enough or no abstract was available, the full text was examined. Following discussion between JH and RB, 138 sources not fulfilling the

¹ Following the initial search period (Mar–Dec 2014), the paper was drafted but not completed. Subsequently, there was a gap for personal reasons, and the team felt that it was then appropriate to conduct the same search again to ensure that it was as current as possible (Jan–Feb 2016). This second search was carried out using the same terms by the same researcher.

Table 1
Database search strategy.

| | |
|------------------------|--|
| Databases | Embase, Psycinfo, Medline, CINAHL, Web of Knowledge, ASSIA, Web of Science, and SCOPUS |
| Sample | parent* OR mother* OR father* OR family OR families OR child* OR adolescent* OR teen* OR young people or sibling* |
| Phenomenon of interest | epileps* |
| Design | interview* OR focus group* |
| Evaluation | view* OR experienc* OR opinion* OR attitude* OR perce* OR belie*OR feel* OR know* OR understand* |
| Research type | qualitative |
| Final search strategy | parent* OR mother* OR father* OR family OR families OR child* OR adolescent* OR teen* OR young people or sibling* AND epileps* AND interview* OR focus group* OR view* OR experienc* OR opinion* OR attitude* OR perce* OR belie*OR feel* OR know* OR understand* OR qualitative |

inclusion criteria were excluded. Where more than one source utilized the same primary data, the original source was used, resulting in the removal of one further source leaving twenty-one sources (eighteen peer-reviewed primary journal articles and three theses) for inclusion in the review (Table 4).

2.3. Data extraction and synthesis

The following data were extracted for each study: author, year, country or origin, study aims, sample population, research methods, and key findings. From the data extracted, JH synthesized information relating to the study populations: which family members were included; age, gender, socioeconomic status, ethnicity, seizure type and frequency, duration and onset of epilepsy, and study exclusion criteria. Following this, a thematic synthesis of the study findings was conducted [12]. The findings/results, and the information presented on participants and methods from each study, were first read by JH and RB. Initial themes within the findings of each study were identified independently. The initial themes were then compared across the studies, and agreement reached on the synthesis of themes under two broad main headings – impact of epilepsy and coping with epilepsy. Subthemes were identified as the following: physical and emotional impact, impact on everyday activities, impact on social relations, knowledge about epilepsy, prevention of seizures, managing social relations, and support. The final step involved ‘going beyond’ [12] the simple description of the themes and research information in order to present a discussion of the implications of the review findings and any recommendations arising from the review. This was achieved through whole-team discussions.

2.4. Critical appraisal

Alongside the data extraction and synthesis, the quality of the studies included was assessed by JH and RB using established criteria to evaluate the quality of reporting and the appropriateness of the methodology and methods adopted [12]. Given the focus of this review, specific attention, where appropriate, was given to the consideration of issues raised when researching with children. Critical appraisal was not used to exclude articles from the review. As the overview indicates, the quality of the studies was generally high (Table 3). Moreover, it is recognized that, while there are tools to appraise qualitative research, there is not an appropriate empirically tested method for excluding qualitative studies on methodological grounds [12–14]. Appraisal tools “should be utilized as part of a process of exploration and interpretation in the synthesis process” [13]. It is common practice for methodological concerns to be highlighted and presented in the review findings rather than excluding articles from reviews (for an example see [15]). In this review, the appraisal tool was used to highlight methodological issues in relation to reporting and conducting research involving children

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