



## Review

## A systematic review of quality of life in parents of children with epilepsy

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## ARTICLE INFO

## Article history:

Received 24 January 2018

Revised 5 March 2018

Accepted 6 March 2018

Available online xxxx

## Keywords:

Family

Caregiver

Pediatric

Childhood onset

Mental health

QOL

## ABSTRACT

**Objectives:** This systematic review aimed to 1) describe the quality of life (QOL) of parents of children with childhood-onset epilepsy (CWE), 2) identify factors associated with parental QOL, and 3) evaluate the association between parents' QOL and children's psychological well-being.

**Methods:** We conducted a comprehensive search of MEDLINE, EMBASE, and PsycINFO and conducted forward and backward citation tracking. A total of 15 articles met inclusion criteria. Parents' QOL was compared with population norms, healthy controls, and parents of children with other chronic conditions. Factors associated with parental QOL were systematically evaluated.

**Results:** Heterogeneity in study design and reporting prevented a meta-analytic synthesis of results. The majority of studies found that parents of CWE had poorer QOL relative to healthy controls or population norms and similar QOL as parents of children with other chronic conditions. In addition, poorer parental QOL was consistently associated with greater parental anxiety and depressive symptoms and poorer socioeconomic status and child QOL. Mothers had poorer QOL relative to fathers. Seizure control was not consistently associated with parental QOL. Results highlight the impact of family environment and psychosocial factors.

**Significance:** This review suggests that parents of CWE have compromised QOL. The results are in line with previous research showing the interdependent nature of psychosocial and medical factors, with psychosocial factors playing a critical role in child and parental QOL and well-being. Interventions targeting the family unit are warranted, and healthcare providers should be aware of the bidirectional relationship of epilepsy, family environment, and child/parent health and well-being.

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## 1. Introduction

Childhood-onset epilepsy extends beyond seizures, with children experiencing a wide range of cognitive, psychiatric, and behavioral comorbidities that often go underrecognized and untreated [1–3]. In addition, families of children with epilepsy (CWE) have been found to experience greater stress, poorer quality of parent–child relationships, lower parenting confidence, and more problems in family functioning, adaptation, and relationships, relative to other families [4]. Recent systematic reviews of parents of CWE report that up to 58% score in the clinical range for anxiety symptoms [5], and up to 50% of mothers are at risk for clinical depression [6]. Importantly, psychosocial factors,

family environment, and parental well-being often have a greater impact on children's health-related quality of life (QOL), depression, anxiety, and behavioral problems than epilepsy-related factors [4–10]. This finding is echoed in other childhood chronic conditions, where the most important factors for adaptation and well-being are individual and family characteristics, rather than illness characteristics [11]. However, epilepsy-related characteristics remain important in understanding parental outcomes. The Caregiving Process Model adapted for CWE [12,13] aids in the conceptualization of the complex interplay between epilepsy, individual, and family characteristics, and ultimately, the manifestation of parental outcomes, namely QOL. In this model, the first domain consists of youth/clinical characteristics (e.g., illness severity, time since diagnosis, comorbidities), family environment (e.g., financial status, education, employment), parents' psychosocial factors (e.g., caregiver strain, stress response to youth's illness), and the interactions between these factors. These factors impact the second domain, coping resources (e.g., self-efficacy, social support), followed by

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management behaviors (e.g., treatment plan management, lifestyle behaviors, interactions with healthcare providers), and ultimately lead to caregiver outcomes (e.g., QOL, physical symptoms, psychological symptoms, functional status).

Although the majority of past studies and systematic reviews have focused on symptoms of anxiety and depression in parents of CWE, little is known about their QOL. Health-related QOL is a multidimensional construct encompassing the individual's subjective perception of their physical health, psychological well-being, social functioning, and independence [14]. Although symptoms of depression and anxiety may impact health-related QOL, instruments developed to measure health-related QOL reflect individual perceptions of the influence of disease and treatment on function and are not interchangeable with instruments that measure symptoms or impairments, such as measures of anxiety and depression [15,16]. Health-related QOL is an important construct in understanding how parents respond, adapt, and cope with the challenges of childhood-onset epilepsy and other stressors, as conceptualized by the Caregiving Process Model, and may provide targets for potential interventions. To date, there have been no reviews evaluating the QOL of parents of CWE.

The current study aimed to provide a succinct review of the literature evaluating the QOL of parents of CWE, an area of research that has been neglected and warrants further research. Specifically, the primary aim was to systematically review the literature to describe QOL for parents of children with childhood-onset epilepsy. Our secondary aims were to identify factors associated with parental QOL and to evaluate the association between parents' QOL and their children's psychological well-being, namely QOL, depression, and anxiety. We hypothesized that 1) parents of CWE will have poorer QOL relative to healthy controls, 2) the most proximal factors to parental outcome, as outlined in the Caregiving Process Model, would have the largest impact on parental QOL, and 3) parents' QOL will be strongly correlated with their children's psychological well-being.

## 2. Methods

### 2.1. Definition of QOL

As mentioned, health-related QOL is a broad construct that encompasses many domains of life, including physical health, psychological well-being, social functioning, and independence. Health-related QOL is thought to be encompassed within the larger construct of QOL, which reflects individuals' perception of their position in life, within the context of culture and value systems in which they live and in relation to their goals, expectations, standards, and concerns [17]. In contrast, health-related QOL is focused on the impact of illness and treatments on a person's life and does not pertain to aspects of life that cannot be influenced by healthcare intervention, such as environmental quality and political stability [18]. The current review was inclusive of studies evaluating health-related QOL specifically or QOL more generally.

### 2.2. Search strategy and study selection

We conducted a comprehensive search of MEDLINE (Ovid), EMBASE (Ovid), and PsycINFO on May 5, 2017, using a combination of subject headings and keywords relating to 1) QOL, 2) epilepsy, and 3) parents. Specifically, we searched for (exp "Quality of Life"/ or quality of life), and (exp Epilepsy/ or epilepsy), and (exp Parents/ or parent\* or mother or maternal or father or paternal) and restricted the search to studies on humans and published in English. There were no date restrictions. To ensure no records were omitted from the search strategy, reference lists of all included studies were manually searched (backward citation tracking), and Web of Science, Scopus, and Google Scholar were used to identify articles citing the articles included in this review (forward citation tracking). In addition, alerts were set on Google Scholar to identify

studies published after the search date using the terms (quality of life) and (epilepsy) and (parent\* or mother or maternal or father or paternal). This alert was discontinued on December 31, 2017.

Articles were included if they quantitatively reported on the QOL of parents (or guardians) of individuals with childhood-onset (<18 years of age) epilepsy. Review articles, case studies, and conference abstracts were excluded; we contacted authors of abstracts of unpublished studies to determine whether the studies had been published subsequently in a peer-reviewed journal, though no eligible studies were identified using this method. Among the conference abstracts excluded, no information on parents' QOL was available to be extracted. All identified articles were screened by two independent reviewers (KP and TPT). First, title and abstracts were checked and studies reporting, or thought to potentially report, on the QOL of parents of individuals with childhood-onset epilepsy were retained; inter-rater reliability was  $\kappa = 0.46$ . Second, the full text of each article was checked, and studies meeting inclusion criteria were retained; inter-rater reliability was  $\kappa = 0.85$ . Any disagreements between reviewers were discussed among the two reviewers and resolved by consensus.

### 2.3. Quality check

All included studies were evaluated by two independent reviewers (KP and TPT) using a modified version of the Downs and Black Quality Index [19]. Items specific to intervention studies, such as randomization and blinding, were removed, reducing the Quality Index to 15 items. The modified index is presented in Table S1 and has been used by past systematic reviews on similar topics [6]. The Quality Index is composed of four subscales: reporting quality, external validity, internal validity, and statistical power. Each checklist item was scored as 0 (no/unable to determine) or 1 (yes), where higher scores reflect higher methodological quality.

### 2.4. Data extraction and synthesis

Data relevant to describing patient and parent characteristics, parental QOL, and factors associated with parental QOL were extracted by one reviewer (KP) and verified by a second independent reviewer (TPT). When methodological questions arose or if more detailed data were required, corresponding authors were contacted; of the 12 corresponding authors contacted, 7 responded, though the requested information was not always available. Although the Short Form health survey (SF-36 or SF-12) was employed by eight studies to evaluate parental QOL, the available data, the heterogeneity in patient samples, and the subscales reported did not allow for a meta-analysis. Similarly, in evaluating factors associated with parental QOL, operationalization of the factors, analyses used, and data reported varied among studies, which did not allow for a meta-analysis. Results of univariable and multivariable analyses were reported for each study. Results of univariable analyses were combined and presented for the factors that were examined in at least two studies. Similar methods have been utilized by prior systematic reviews and meta-analyses evaluating risk factors [20].

## 3. Results

### 3.1. Search results

The Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines were followed [21]. The search strategy identified 709 records, 62 of which underwent full-text screening, and 11 met the inclusion criteria (Fig. 1). Forward citation tracking identified one additional article, and the automated alerts of studies published after the search date identified three articles. Therefore, 15 articles were included in this systematic review [22–36].

Some articles reported on different aspects of the same study, utilizing the same parent sample. In these cases, we aimed to include as much

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