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The impact of childhood epilepsy on quality of life: A qualitative investigation using focus group methods to obtain children's perspectives on living with epilepsy

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ABSTRACT

As children's perceptions of their quality of life are unique, it is essential to elicit their concerns directly rather than from proxy informants. This study therefore aimed to investigate the impact of childhood epilepsy on quality of life directly from the child's perspective. Focus group techniques and qualitative analysis were utilized. Twenty-two children between 7 years 4 months and 12 years 6 months of age (11 females, 11 males) were stratified by age (7–8, 9–10, 11–12 years) into five focus groups. Data were transcribed and analyzed using grounded theory techniques to generate themes and categories. Themes were presented using the children's language. Two major themes were identified, "things to do with growing up" and "things to do with epilepsy," with five and four subthemes, respectively. No significant age-related differences were found. A conceptual model illustrates these findings, and comparisons are made to previous research with adolescents using similar methodology.

1. Introduction

Health is defined as "a state of complete physical, mental and social well-being, and not merely the absence of disease or infirmity" [1]. The development of the construct of quality of life (QoL) has been influenced strongly by this biopsychosocial approach. The four domains of QoL are disease state and physical symptoms, functional status, psychological functioning, and social functioning [2]. QoL is defined as "the individual's perception of their position in life, in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns" [1, p.5]. This may also be stated as how the individual evaluates his or her QoL in relation to his or her personal expectations [3]. Health-related quality of life (HRQoL) examines the subjective and objective impact of dysfunction associated with an illness, injury, or medical treatment [3], by differentiating health from more generic social and environmental issues. To achieve this, measures of HRQoL must address limitations on current development, restrictions on everyday activities, and detrimental effects on future achievements.

Epilepsy is often a chronic and debilitating condition, yet the use of quality of life measures in epilepsy research is relatively recent compared with that in other chronic conditions [4], particularly within the pediatric population. Epilepsy is the most common serious neurological disorder in childhood [5] and can be associated with profound deleterious psychological and sociological consequences, often not directly related to the clinical features of the disorder such as seizures. These consequences include stigma, limitations on daily activities, and the fear of impending seizures leading to feelings of insecurity, which in turn can adversely affect healthy social development. In childhood epilepsy, relationships can be compromised by overprotective parenting preventing the skill acquisition necessary for a full and independent lifestyle [6]. Children with epilepsy have been found consistently to be more behaviorally disturbed, with lower self-esteem, and to experience poorer academic attainment than children with diabetes or asthma [7,8]. These findings indicate that children's health and development are enmeshed with their psychosocial environment. With so many potential negative consequences in all areas of life, it is crucial to investigate children's perceptions of their epilepsy and of themselves. Such evaluation of quality of life in children with epilepsy could highlight the need for additional professional resources and lead to early intervention.

People's perceptions of their QoL are unique. Eliciting concerns directly from the individual, and not through proxy informants, is therefore paramount to obtaining a comprehensive account of patient experience [9]. Few QoL articles are relevant to children and most use proxy informants to report children's QoL [10]. In order to meet the needs of children it is essential to understand the child's perspective of the limitations imposed by his or her illness. The children themselves can complete few QoL measures, and of those available, most are suitable for children over 8 years of age. Many chronic illnesses affect children before this age and early

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experiences are likely to have an impact on long-term outcomes. Proxy informant approaches assume that children's perceptions of the world and their priorities in life are likely to be the same as adults [9]. Children and their doctors or proxy informants have been shown to disagree with each other, particularly on subjective dimensions in studies of HRQoL [11]. As well as obtaining the individual's personal perspective, QoL measures must be sensitive to the changes that occur throughout development [9], as well as assessing problems that arise across the range of severity of epileptic conditions [6].

McEwan et al. examined the quality of life of adolescents with epilepsy, utilizing focus group methods [12]. Two main themes were developed, comprising issues relating to adolescent development or "identity formation" and epilepsy-related variables. No significant age-related differences in issues were identified. By far the greatest impact on the adolescent's QoL involved the negative impact on peer relationships and the development of autonomy and independence. These findings were consistent with previous research [13–17]. Children and adolescents have been found to have different views about health and illness, yet several concerns may transcend these age groups [18].

Qualitative research is powerful because it enables experiences to be investigated uniquely from the individual's perspective. Focus groups provide a setting to investigate these perspectives. The goal of a focus group is to elicit a discussion in a permissive and nonthreatening environment, thus allowing the researcher to view the world from the participant's perspective [19]. Focus group methodology provides a "bottom–up" approach to generate themes of concern, as opposed to predetermined areas of discussion, and avoids the need for participants to complete questionnaires. Focus groups are potentially useful in pediatric populations as they remove the emphasis on the adult–child relationship, therefore reducing responder bias [20]. The pressure to respond is also removed as the focus group continues regardless of individual response rates [21]. As the method acknowledges the child as the expert, the results are likely to have high face validity [22]. However, because younger children have shorter attention spans, focus groups need to adapt accordingly to prompt discussion and maintain concentration. Prompt questions need to relate directly to children's experiences and use concrete examples [23]. Research has shown that when questioned in appropriate ways, children's recall of life events is reliable and that, given the opportunity, they are accurate reporters of their physical and mental health [23,24]. The focus group method therefore provides an appropriate medium to establish what QoL means to children and to ascertain whether this is a useful concept.

2. Aims and design

This study aimed to use qualitative methods to investigate children's perceptions of the impact that epilepsy has on their QoL, by developing a comprehensive list of themes through qualitative analysis.

The specific aims of this study were:

- to identify the impact epilepsy has from a child's perspective,
- to identify age-specific concerns in childhood epilepsy,
- to identify general concerns in childhood epilepsy, and
- to construct an epilepsy-related QoL model from the identified themes to enhance understanding of childhood epilepsy.

The study was adapted from the methodology used successfully with an adolescent population with epilepsy [12] and was designed to meet the quality criteria for qualitative research using the Critical Appraisal Skills Programme guidelines [25]. Participants were stratified by age into three age groups (7–8, 9–10, 11–12 years) to identify age-specific variations and to encourage peer discussion [23]. As most researchers conclude that focus groups are unsuitable for children less than 6 years of age, because they do not have the social or language skills to be effective participants in group discussions [26], this stratification was intended to ensure all concerns were identified across the developmental span while providing valid data. Children over 6 years of age were likely to be suitable participants as they would provide spontaneous and less socially desirable responses than adult participants [26]. The upper age limit of 12 years was chosen as we aimed to focus on issues directly relevant to younger children. We also aimed to build on the earlier work by McEwan et al. in adolescents. It has been recommended that four or five participants per focus group are desirable to ensure at least three "talkers" [27]. Other literature suggests groups of four to six and that group time length should be 45 min for children under 10 and 60 min for children between 10 and 14 [23,26,28].

Focus groups were utilized therefore to facilitate the generation of key concerns. They provided an open, free, and relaxed format for the children to express their views. The groups were small, relatively homogeneous, informal, and aimed to elicit participants' perceptions, feelings, attitudes, and ideas. Scripts from each focus group were transcribed and thematically coded to identify generic and age-specific themes. We planned to run focus groups until "theoretical saturation" was achieved. Theoretical saturation is the point at which no new categories, concepts, dimensions, or incidents emerge during the theory development process, therefore implying that the research questions had been fully answered [29]. Power calculations are not appropriate in qualitative research as sample size is not predetermined. The number of focus group participants required to answer the research question was determined during the research process.

3. Methods

3.1. Participants

A total of 22 children (11 male, 11 female) between the ages of 7 years 4 months and 12 years 6 months participated in the study (mean age: 9 years 6 months). There were 9 participants in the 7- to 8-year-old group, 9 in the 9- to 10-year-old group, and 4 in the 11- to 12-year-old group. Total sample characteristics as well as characteristics for each age group can be viewed in Table 1.

As can be seen in Table 1, 11 of the participants experienced partial seizures, and 14 experienced generalized seizures, with a mean age of diagnosis of 6 years 1 month. Three of the children experienced more than one seizure type. Seizure frequency was varied, with 11 of the participants having seizures on a daily to monthly basis, 9 of the participants having seizures several times a year to once a year, and 2 of the participants reportedly seizure free. Two of the children experiencing seizures were not taking antiepileptic medication, and 2 received polypharmacy.

Participants were selected from the epilepsy database of a pediatric neurosciences center in Glasgow: the Fraser of Allander Neurosciences Unit at the Royal Hospital for Sick Children. Participants were included if they: (a) had a diagnosis of epilepsy (controlled and noncontrolled) of at least 6 months' duration and were between the ages of 6 and 12 years; (b) were able to verbally participate in a group, as information was mainly gathered through verbal discussion; and (c) were in mainstream schooling, to attempt to minimize confounding variables and therefore increase the validity of this study. Participants were excluded if they had: (a) other neurological disorders; (b) non-epileptic attack disorder (including those with a dual diagnosis with epilepsy); and (c)