



The challenges that parents of children with epilepsy face: A qualitative study



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ARTICLE INFO

Article history:

Received 6 October 2016

Revised 20 April 2017

Accepted 22 April 2017

Available online xxxx

Keywords:

Epilepsy
Parent
Child
Disclosure
Qualitative research

ABSTRACT

Objective: This qualitative study explored the challenges that Greek parents/caregivers of children with controlled epilepsy (CwE) face regarding the disorder.

Methods: Interviews were conducted based on open-ended questions guided by a review of the literature. A total of 91 parents/caregivers were recruited by neurologists at the neurology clinics of two Athens public hospitals. A hermeneutic phenomenological approach was used to explore parent/caregiver experiences. The data were grouped and analyzed through a textual interpretation.

Results: Two key challenges were identified for parents of CwE: the disclosure of epilepsy and the absence of adequate information about coping with epilepsy. Parents in Greece were hesitant to reveal their child’s epilepsy to school staff and their wider social milieu. Also, although satisfied with the patient-centered approach they experienced with their hospital doctor, parents/caregivers found that they needed more education about the existing sources of psychosocial and emotional support to cope with their child’s epilepsy personally and as a family. Finally, the parents/caregivers who let their child know about the epilepsy and discussed the implications with the child found that parent–child communication improved.

Conclusion: This study provides valuable insight into the impact of epilepsy on parents of CwE, which might help hospital and school staff support families with greater understanding, sensitivity, and skill. The findings suggest that Greek authorities should staff hospitals and schools with experts and more systematically advertise sources of information about epilepsy and ways to cope with it.

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1. Introduction

It is widely accepted that epilepsy is a disorder that affects not only patients but also their families [1–3]. With regard to children with epilepsy (CwE), apart from a negative impact on the child’s social relationships and psychosocial well-being, studies document disruptions in family relations [4–7]. CwE express frustration with their parents’ constant

supervision, restriction of activities and overprotection, and with feelings of difference from their peers [8]. However, children living with epilepsy often rely on their parents/caregivers for guidance related to their condition, especially when it comes to the disclosure of their disorder [4,8,9]. Moreover, when the disclosure of the diagnosis is referred to those external to the nuclear family, CwE expressed anxiety, apprehension, and contentment with the negative response to disclosure [10]. At the same time, parents/caregivers seek help mainly from the medical staff about the management of their CwE condition [11]. However, the time that an expert spends with the patient and their family is limited due to daily work pressures. Also, physicians may provide information that does not meet the needs of the parents/caregivers because it does not address their specific concerns [12–15]. It is, therefore, important for the medical personnel to be aware of the parents/caregivers’ concerns

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about their child's epilepsy to provide them – in the minimum available length of time – with appropriate counseling and offer them all of the guidance they need to develop better family relations [15–17]. Parents' feelings and reactions towards their child's epilepsy are very important because it is the benchmark for the child's attitude towards the disorder. This connection arises because the children are very much influenced by their parents' attitude towards their condition [4]. Thus, a comprehensive investigation into the challenges faced by parents/caregivers of CwE is required to synthesize parents' concerns in the context of time-consuming parental guidance sought from healthcare professionals [18].

The information-seeking on the part of the parents/caregivers of CwE resulting from their evaluation by medical personnel brings together sociology and medicine. Sociology, as a “calculated observation which defines identities, their socially constructed meaning, relevant interpretations, and the resulting interaction,” is a science that focuses on an action adaptable to the situations, involving the observer's understanding [19]. Medicine, as the science and practice of the diagnosis, treatment, and prevention of disease, encompasses a variety of healthcare practices to maintain and restore health by the prevention and treatment of illness [20]. Both disciplines follow different methodologies. However, some of the differences in methods between medicine and sociology still rely on the same practices, such as observation, to reach their targets. Furthermore, natural scientists are much more likely than social scientists to rely on formulations that are more quantitative and precise. Sociologists, who are often satisfied to link two variables, gain their satisfactory explanations more through interaction with the subject or through sharing the subject's experiences than through logically precise explanations relying on mathematical modeling [21]. Health practitioners evaluate knowledge and experience from sciences such as sociology to better perform their role and achieve further competence in their daily work [22,23].

In light of the role for sociology in healthcare understanding, this qualitative study relied on sociological methods to explore the challenges that Greek parents/caregivers of CwE face to provide useful knowledge for healthcare professionals about this population's needs. To our knowledge, based on literature searches of relevant databases, this is the first qualitative study conducted in Greece of the challenges that Greek parents/caregivers of CwE face.

2. Methods

2.1. Study site

For the literature review of the field, we used the PubMed and Iatroteck databases with the following keywords: ‘parents of children with epilepsy’, ‘qualitative study’, ‘epilepsy and qualitative study’, ‘parents, epilepsy and qualitative study’, and ‘epilepsy disclosure’. Studies were limited to English language, accessible full text, and those that addressed parent or caregiver of CwE (age up to 18 years old) concerns and used qualitative methods. Among the relevant articles we identified, none referenced Greek parents' concerns about CwE.

Afterwards, we conducted a qualitative study, based on open-ended question interviews, from October 2011 to November 2013, in two Athens public hospitals: Evangelismos and Children's Hospital Panagiotis & Aglaia Kyriakou. The study was conducted in a prospective manner, recruiting parents of consecutive patients from the outpatient clinics of the referred hospitals.

The referred hospitals are sited in the capital city of Greece, and patients from the entire country are referred there.

2.2. Study participants

To recruit our research participants, from October 2011 to November 2013, we contacted 100 parents/caregivers of CwE whose children were

consecutive patients of the outpatient neurology clinics of the referred hospitals, if they met the following criteria:

1. Child age 5 to 17 years with epilepsy during school age (although diagnosis could have occurred at any time since birth).
2. Child with controlled epilepsy [24] and no significant intellectual disabilities, learning difficulties, and/or developmental delay, and attending regular school.
3. Parent/caregiver who lived with the child and personally cared for him/her.
4. Parent/caregiver who was mentally and physically healthy.
5. Parent/caregiver willing and able to participate in the study.

Finally, 91 parents/caregivers were recruited for our study; two parents/caregivers did not want to participate, three failed to participate due to work schedules, three parents/caregivers did not meet all referral criteria, and one parent withdrew after the interview.

Before any subject's recruitment, there was an evaluation from professionals of each clinic to check if they met the required criteria.

2.3. Data collection

For the objective of our research, a qualitative study was chosen because this approach provides an effective methodology to investigate experiences from the perspectives of the individuals [25]. We conducted in-depth interviews with open-ended questions to let parents express their concerns and share their experiences with us. Thus, we could gather ‘deep’ information and perceptions of personal knowledge and subjectivities, gaining insights into the everyday lives of parents of CwE. If both parents wished to participate, they were given the option of being interviewed separately or together.

First, we interviewed 10 participants, taking a phenomenological approach [26–31] as a way to identify parents/caregivers' main concerns. Phenomenology is “... the rigorous and unbiased study of things as they appear so that one might come to an essential understanding of human consciousness and experience ...” [28]. Using this approach, our aim was to explore the experiences of the interviewees, leaving out any preconceptions of the researcher.

Parental concerns reflected two themes and their subthemes that emerged from the content analysis. To ensure validity and credibility, we decided to conduct further interviews until the research process reached a theoretical saturation point. As Mack defines, saturation is the point in data collection when new data gathered by conducting further interviews no longer bring additional insights to the research questions [25].

We therefore continued with a hermeneutic phenomenological approach based on van Manen's theory [26,27] because phenomenology does not attempt to generalize or create theory; rather, it reveals the life-world through language [26,30]. The van Manen theory allows us not only to detect the lived experiences but also to interpret and understand the described experiences as the interviewees reflect on them. With this approach, we interviewed more parents/caregivers to enrich and triangulate our data. Another 81 parents/caregivers were interviewed with open-ended questions until the process reached the theoretical saturation point.

Given that the 91 parents came from all Greek counties (even from isolated areas of Greece), issues related to the stigma of epilepsy associated with the parents' home location were checked in respect to the challenges they face having a CwE. The participants were interviewed with the same basic questions to triangulate the two main themes and the subthemes we had already identified from the first 10 interviews.

During the 91 total interviews, the interviewer introduced the subject of the discussion, explained the purpose, and obtained written consent of the parent/caregiver. Ethical guidelines of anonymity were followed, and the parents/caregivers were informed of these guidelines before giving their consent. Some of the parents/caregivers did not want their

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