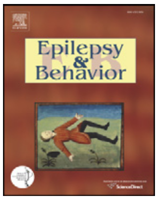
Epilepsy & Behavior 37 (2014) 191–197

Contents lists available at ScienceDirect

Epilepsy & Behavior

journal homepage: www.elsevier.com/locate/yebeh



Zoning in on parents' needs: Understanding parents' perspectives in order to provide person-centered care

Jana E. Jones [a,*], Alanna Kessler-Jones [a], Mary K. Thompson [b], Kate Young [a], Amelia J. Anderson [c], David M. Strand [d]

[a] University of Wisconsin School of Medicine & Public Health, Department of Neurology, 1685 Highland Ave., Madison, WI 53705, USA
[b] University of Wisconsin Department of Continuing Studies, 21 N. Park Street, Madison, WI 53715, USA
[c] University of Kentucky, College of Medicine, Department of Neurology & Neurosurgery, 740 S. Limestone Street, Kentucky Clinic L-454, Lexington, KY 40536-0284, USA
[d] University of Wisconsin, Department of Rehabilitation Psychology and Special Education, 431 Education Building, 1000 Bascom Mall, Madison, WI 53706-1326, USA

ARTICLE INFO

Article history:
Received 3 March 2014
Revised 19 June 2014
Accepted 22 June 2014
Available online 20 July 2014

Keywords:
Pediatric epilepsy
Parents
Person-centered care
Qualitative study
Comorbidities

ABSTRACT

Purpose: In order to develop a theoretical framework for person-centered care models for children with epilepsy and their parents, we conducted a qualitative study to explore and understand parents' needs, values, and preferences to ultimately reduce barriers that may be impeding parents from accessing and obtaining help for their children's co-occurring problems.

Methods: A qualitative grounded theory study design was utilized to understand parents' perspectives. The participants were 22 parents of children with epilepsy whose age ranged from 31 to 53 years. Interviews were conducted using open-ended semistructured questions to facilitate conversation. Transcripts were analyzed using grounded theory guidelines.

Results: In order to understand the different perspectives parents had about their child, we devised a theory composed of three zones (Zones 1, 2, and 3) that can be used to conceptualize parents' viewpoints. Zone location was based on a parent's perspectives on their child's comorbidities in the context of epilepsy. These zones were developed to help identify distinctions between parents' perspectives and to provide a framework within which to understand parents' readiness to access and implement interventions to address the child's struggles. These zones of understanding describe a parent's perspectives on their children's struggles at a particular point in time. This is the perspective from which parents address their child's needs. This theoretical perspective provides a structure in which to discuss a parent's perspectives on conceptualizing or comprehending the child's struggles in the context of epilepsy. The zones are based on how the parents describe (a) their concerns about the child's struggles and (b) their understanding of the struggles and (c) the parent's view of the child's future.

Conclusions: Clinicians working with individuals and families with epilepsy are aware that epilepsy is a complex and unpredictable disorder. The zones help clinicians conceptualize and build a framework within which to understand how parents view their child's struggles, which influences the parents' ability to understand and act on clinician feedback and recommendations. Zones allow for increased understanding of the parent at a particular time and provide a structure within which a clinician can provide guidance and feedback to meet parents' needs, values, and preferences. This theory allows clinicians to meet the parents where they are and address their needs in a way that benefits the parents, family, and child.

1. Introduction

Many parents who have a child with epilepsy willingly provide stories of daily struggles. When queried, parents often discuss how they are adjusting to the diagnosis of epilepsy in their child. When the seizures are reduced by medications, parents are grateful for good seizure control. However, parents continue to report ongoing struggles related to learning problems, social difficulties, attention problems, organizational problems, irritability, anxiety, and depressive symptoms. In a study of children with recent-onset epilepsy, rates of Axis I disorders were reported to be as high as 69% [1]. Additionally, a number of studies have shown that when a child with epilepsy has a co-occurring condition like anxiety, depression, ADHD, or an intellectual disability, parents experience higher rates of stress [2–6]. Importantly, parents frequently report that they are unable to access the appropriate services or are

---

[*] Corresponding author at: University of Wisconsin School of Medicine & Public Health, Department of Neurology, 1685 Highland Ave, Medical Foundation Centennial Building, Room 7229, Madison, WI 53705, USA. Tel.: +1 608 262 5481; fax: +1 608 265 0172.
E-mail address: jejones@neurology.wisc.edu (J.E. Jones).

http://dx.doi.org/10.1016/j.yebeh.2014.06.029

unable to receive guidance regarding the child's co-occurring problems. Parents are often dismayed and seem at a loss regarding what steps to take to address problems [7].

As part of a recent pilot intervention study designed to address some of the problems parents were reporting [8], we found it unexpectedly difficult to recruit for the study, and this recruitment problem was in significant contrast to the request for assistance that had been put forth when talking with parents prior to study implementation. We were puzzled by this difficulty because parents were asking for assistance and guidance, but, surprisingly, few parents were taking advantage of an opportunity to get help. We looked to the literature to provide insight into what we were experiencing. Wu et al. [9] indicated that parents were well aware of their child's co-occurring behavioral problems, but only 1/3 of the children received treatment for the comorbid conditions [10]. Roeder et al. [11] reported a similar experience where parents were informed of their child's diagnosis of depression, but only a third of those children received treatment. It appeared as though there was a disconnection between parents describing the child's problems and accessing help to address those problems. Research creates its own barriers to participation, but the nonresponses we were experiencing appeared incongruent compared with what parents were reporting as struggles and their repeated requests for help.

As is well documented, epilepsy is commonly accompanied by psychological, cognitive, social, and physical complications. It is important for clinicians to provide information and assistance to the individual and family that will promote well-being and enhance quality of life [12]. As a result, it is important for individuals with epilepsy and families to have patient-centered care that has a coordinated and comprehensive approach to meet the needs of each person and family [12]. Patient-centered care is often defined as care that addresses the needs, preferences, and values of the individual and family. The IOM report [12] also challenged clinicians to provide individuals and families with appropriate and accurate information regarding the co-occurring problems that frequently accompany epilepsy. Additionally, it is important that clinicians provide information to individuals and families that is approachable and understandable. However, very little information is available regarding how clinicians can begin to develop patient-centered approaches to meet the individual needs and values of each family. How do clinicians conceptualize and understand the needs, values, and preferences of a family? Are there any tools that can assist a clinician in the process? What can parents tell us to help us understand their needs and perspectives?

In order to develop a framework for person-centered care models for children with epilepsy and their parents, we conducted a qualitative study [13] to explore and understand parents' needs, values, and preferences to ultimately reduce barriers that may be impeding parents from accessing and obtaining help for their children's co-occurring problems. This study aimed to develop a theoretical framework to aid clinicians and researchers to more effectively work with parents to address their children's needs, utilizing person- and family-centered care models.

2. Methods

2.1. Data analysis

We utilized a grounded theory approach to analyze the relationship between concepts as related to parents' understanding of epilepsy in the context of their children [14]. Grounded theory was utilized because little is known about the interview results, and we wished to avoid restricting ourselves to current hypotheses or inferences from prior knowledge or studies. The research team coded the data, and the team consisted of six researchers, which included the 2 interviewers, as well as a qualitative study research facilitator (MKT). Transcripts were coded across incidents, allowing us to see how seemingly dissimilar events shared a common core. As part of the deductive process and to verify our substantive coding, we looked at the problem as it was conceptualized by the parents. For example, we looked at all incidents related to how the parents grappled with the struggles. Our research team compared the data, constantly modifying and sharpening the growing understanding of the parents' concerns. As we progressed, axial coding was used by putting the first group of 10 transcripts into categories to examine emerging ways parents conceptualized their concerns. During the selective coding process, we sought to identify the core explanation for the parents' behavior in resolving what they thought was the main concern about the child. After identifying the core categories, we theoretically sampled the rest of the dataset, ensuring that our connections between parents' concerns continued to make sense in the emerging hypothesis. Our aim was not for the “absolute truth” but rather for trying to conceptualize what was occurring from the parental perspectives. Theoretical codes emerged from constantly comparing the data across field notes and memos; we integrated fractured concepts into a hypothesis that worked to explain the main concerns of the participants [14]. Memos assisted the research team in theorizing the write-up of ideas that came from our substantive and theoretical coding. Our team used memoing to analyze data and to look at the relationship of ideas and how these concepts were compared across categories to ensure that our hypothesis was more than just a superficial understanding of the parents' main concerns.

Theoretical sampling was utilized to analyze the data in order to produce a theory. We coded the first half of the data and sampled the second portion of the dataset to determine if the coding structure was maintained. In terms of saturation, our main goal was to gather enough data until no new categories were emerging within the theory. Our goal focused on the amount of descriptive data more than on the number of people to recruit and was saturated once we started connecting the theoretical model to our qualitative methodologies. This included ethnographic field notes, memos across team members, and discussions over an 18-month period with a variety of clinicians working in the field including senior experts in epilepsy to scrutinize our theoretical model to ensure that we had reached saturation.

To increase the reliability of the data, we used investigator triangulation. We had investigators from different disciplines including an epilepsy clinician–researcher (JEJ), pediatric neuropsychological clinician (AKJ), and a secondary and postsecondary educator (MKT) who served as evaluators. Additionally, experts in the field of epilepsy, psychiatry, education, and psychology were utilized in the peer debriefing process in order to enhance the validity of the emerging grounded theory. An iterative process was used in order to ensure that parents' perspectives were not placed in stages, in hierarchies, or on a continuum. We examined many theoretical models outside the field of epilepsy to ensure that our emerging theory was additive and distinctive in nature in explaining parents' understanding. Reflexivity was utilized throughout the research process. Preconceptions and assumptions were continually discussed as part of the formulation process. Memo writing was part of our reflexive process allowing for analytical insight to help the research team have purposeful conversations around the emerging theory [15].

2.2. Interview

Research approval was obtained from the Health Sciences Institutional Review Board at the University of Wisconsin School of Medicine and Public Health. Written informed consent was obtained from the parent participants.

Parents were interviewed by research assistants who were unfamiliar with the participants from the intervention pilot study that served as a pool from which participants were recruited. The open-ended semistructured interview questions were written especially for this study, and questions were utilized to facilitate discussion (Appendix A). We started with semistructured interviews and refined our methods to focus on the landscape of what parents were sharing with us including observational notes, clinical reports, ethnographic field notes, and team discussions [15]. Every attempt was made to