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A dyadic model of living with epilepsy based on the perspectives of adults with epilepsy and their support persons

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ABSTRACT

Epilepsy is a chronic condition that significantly affects the lives of individuals with epilepsy and their support persons, though few studies have examined the experiences of both. To examine these experiences and explore the interpersonal relationships between dyad members, we conducted in-depth interviews with 22 persons with epilepsy and 16 support persons. Data analysis was guided by a grounded theory perspective. We developed a model that shows how epilepsy impacts the lives of both persons with epilepsy and their support persons and how the experiences of persons with epilepsy and supporters influence one another. The core model elements were seizure and treatment factors, relationship characteristics, self-management, seizure control, support provided, illness intrusiveness, and quality of life. Persons with epilepsy moved through the model in five trajectories depending on seizure control, relationship type, and gender. Support providers followed four trajectories based on seizure control, perception of burden, and support for themselves. Persons with epilepsy and their primary support providers have varied experiences in how epilepsy affects their lives. This model could serve as a basis for future research and intervention efforts focused on ways to reduce illness intrusiveness and improve quality of life for persons with epilepsy and their supporters.

1. Introduction

Epilepsy is an intrusive illness that disrupts the valued interests and activities of those people with the condition and their family and friends [1–3]. Persons with epilepsy (PWEs) can experience memory difficulties, adverse side effects from their medication, and functional limitations, such as driving restrictions [4–7]. As a result, PWEs are less likely to be married and to be employed and are more likely to have a lower income compared to people without the condition [8,9]. Persons with epilepsy report feeling isolated and dependent on others, experience interpersonal and social difficulties, and perceive stigmatization due to their condition [7,10,11]. Additionally, PWEs consistently report lower quality of life, higher levels of depressive symptoms, and greater impairment of physical and social functioning compared to people without epilepsy [12–14]. Perceptions of living with epilepsy range from acceptance and living a normal life to feeling a loss of control and giving up hope of recovery [15].

Social support has a positive influence on the health and well-being of PWEs. Higher levels of social support are associated with better quality of life [16–20], improved self-rated health and life satisfaction [21,22], and fewer depressive symptoms [23,24] for PWEs. Additionally, social support contributes to increased self-efficacy to perform epilepsy self-management behaviors [25,26].

Persons with epilepsy rely mainly on parents and spouses, other family members, neighbors, and health care providers for support [27,28]. Support persons can play an important role in providing PWEs with the resources and emotional support needed to deal with and manage epilepsy. For example, support persons give reminders to take medication, monitor medication taking, and support strategies for reducing exposure to triggers [28–30]. The support provided through marriage appears to offset some of the social, functional, and economic challenges faced by PWEs [8]. However, dynamics between support persons and PWEs can also have negative consequences. Bressi et al. [31] demonstrated that while PWEs whose relatives showed warmth had better medication self-management, PWEs who received criticism from their relatives had poor medication adherence.

Despite the important role of support providers, relatively little is known about how epilepsy affects their lives. Epilepsy can cause psychosocial distress and difficulties in all family members and can restrict

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family activities [32,33]. In a survey of 44 families with an adult member with epilepsy, support providers felt that their own support was limited; they received most support from family members rather than from friends or services outside the home [33]. Support providers of PWEs also report low quality of life, particularly for emotional functioning and mental health [34,35]. Support providers' quality of life is largely explained by coping style, which affects their perceptions of their caregiving burden [36]. Other factors that influence a support person's quality of life include perceived social support within the family, PWEs' knowledge of medication, and size of the support person's network [20]. Seizure-related factors appear to have less of an effect on supporters' quality of life [20,36].

Current research on support and caregivers of PWEs has mainly relied on quantitative methods and provides little information from the perspectives of support persons. Further investigation into the role of support persons in the lives of PWEs is important for understanding the effects of support on epilepsy self-management, health outcomes, and quality of life. Additionally, support persons' experiences of living with PWE can shed light on the impact of epilepsy on their own lives. Therefore, the aim of this qualitative study was to use grounded theory to gain insight into the experiences of PWEs and their primary support persons (PSPs). The broader conceptual framework guiding this study was based on the social ecological model, social cognitive theory, and models of social support, all of which acknowledge the influence of support and interpersonal relationships on health and behaviors [37–40]. We were interested in: 1) exploring how epilepsy affects the lives of both PWEs and PSPs and 2) examining the interpersonal relationships between PWEs and PSPs, including the impact of support.

2. Methods

The data used for this analysis were drawn from the qualitative portion of a sequential mixed-methods study, which included a quantitative phase followed by a qualitative phase [41]. The purpose of the overall mixed-methods study was to examine the interpersonal relationship between PWEs and PSPs, support provided and received, and the effects on self-management and mental health. For this analysis, we developed a model based on participants' experiences with living with epilepsy and how the experiences of PWEs and PSPs are intertwined. The methods for this study have been described elsewhere [29,30] and are summarized below. Institutional Review Board approval was received for all study procedures.

2.1. Sample and recruitment

Recruitment occurred at a hospital-based epilepsy clinic from April to November 2011. Interested patients were referred by healthcare providers to the study team, who explained the study and screened for eligibility. Eligibility criteria for PWEs included: 1) being 18 years of age or older, 2) having an epilepsy diagnosis for 3 months or more, 3) being able to identify a primary support person, and 4) being able to speak and read English. Eligible PWEs referred their primary support person. Eligibility criteria for PSPs included: 1) being 18 years of age or older, 2) providing unpaid assistance to a PWE, and 3) being able to speak and read English. Individuals were not eligible if they did not have the cognitive ability to independently provide consent.

2.2. Procedures

Informed consent was received prior to data collection. In the quantitative phase of the study, participants completed a short survey that included measures of epilepsy self-management, support, quality of life, and demographic characteristics. Relevant to this study, depressive symptoms were assessed using the Centers for Epidemiologic Studies Depression scale [CES-D; 42]. The CES-D is a 20-item scale; items are rated on a 4-point Likert scale from rarely (0) occurs most or all of the time (3). The CES-D is reliable and valid in general populations and in samples of PWEs [24,42,43].

Purposive sampling among participants who completed the survey was used to recruit participants for the qualitative phase [44]. At the end of the survey, a subset of individuals – who represented variation in relationship type, gender, race/ethnicity, self-management, levels of support, and depressive symptoms – were invited to complete one in-depth interview. Interviews lasted 45 min on average (range: 20 to 120 min) and were conducted over the phone by one of the researchers (ERW). Phone interviews were chosen to accommodate the transportation limitations experienced by PWEs. Persons with epilepsy and PSPs were interviewed separately. Participants received a $25 gift card to compensate them for their time. Recruitment occurred until saturation of themes – no new information about major themes emerged with new interviews – was achieved [44].

The interviewer used a semi-structured interview guide, which was based on the literature and theoretical framework. The interview guide included similar questions for PWEs and PSPs. The open-ended questions covered experiences with epilepsy, effects of epilepsy on life and relationships, characteristics of the interpersonal relationship, and support provided to the PWEs. Probes were used to prompt the participants for additional information or deeper explanation. All interviews were audio-recorded, de-identified, labeled with a unique identifier, and transcribed verbatim.

2.3. Data analysis

The data analysis utilized tenets of grounded theory methods, which allowed the researchers to identify key concepts and themes inductively and deductively. The constant comparison method commonly used in grounded theory guided the data analysis and model development [45,46]. A codebook was developed deductively, by a priori identifying potential codes from the interview guide, and inductively, through careful reading of the transcripts and line-by-line coding. All transcripts were coded independently by two researchers (ERW and CB or REM), who met regularly to discuss the coding, address any discrepancies, adjust the codebook, and recode transcripts as necessary. Coded sections were continually compared to search for emerging trends in the data. Main categories and the codes that fell under them were identified. Axial coding was utilized to identify relationships between main categories. Analytic memos were written to describe these major categories and explore patterns of experiences [45]. The core categories that emerged included self-management, support, seizure control, illness intrusiveness, and quality of life. Pictorial representations of these relationships and connections were drawn, leading to the development of a model. Finally, we identified the main trajectories that described the ways in which participants moved through the model.

3. Results

3.1. Participant characteristics

In-depth interviews were conducted with 38 individuals (22 PWEs and 16 PSPs) who represented 24 relationships (14 complete pairs, 8 additional PWEs, and 2 additional PSPs). The majority of participants were female (68%) and white (73%) (see Table 1). The average ages of PWEs and PSPs were 33.5 and 50 years, respectively. Most PWEs were not working, whereas the majority of PSPs were working full-time. Over 80% of the pairs lived in the same household.

3.2. The dyadic model of living with epilepsy

The major categories that emerged in the analysis and the relationships between these categories are depicted in Fig. 1. The model shows how epilepsy impacts the lives of both PWEs and PSPs and how the experiences of PWEs and PSPs intertwine and influence one