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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 individuals. To examine these experiences and explore the interpersonal relationships between dyad members, we conducted in-depth interviews with 22 people 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 people with epilepsy and support persons and how the experiences of people 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. People 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. People 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 people with epilepsy and their supporters.

Keywords

epilepsy; social support; self-management; seizure control; quality of life

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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]. People with epilepsy (PWE) can experience memory difficulties, adverse side-effects from their medication, and functional limitations, such as driving restrictions [4–7]. As a result PWE 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]. PWE report feeling isolated and dependent on others, experience interpersonal and social difficulties, and perceive stigmatization due to their condition [7, 10, 11]. Additionally, PWE 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 PWE. 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 PWE. Additionally, social support contributes to increased self-efficacy to perform epilepsy self-management behaviors [25, 26].

PWE 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 PWE 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 PWE [8]. However, dynamics between support persons and PWE can also have negative consequences. Bressi and colleagues [31] demonstrated that while PWE whose relatives showed warmth had better medication self-management, PWE 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 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 PWE 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, PWE's 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 PWE 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 PWE 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 epilepsy 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 PWE and their primary support persons (PSP). 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 PWE and PSP, and 2) examining the interpersonal relationships between PWE and PSP, 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 PWE and PSP, 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 PWE and PSP are intertwined. The methods for this study have been described elsewhere [29, 30] and are summarized below.

2.1. Sample and Recruitment

Recruitment occurred at a hospital-based epilepsy clinic from April–November 2011. Interested patients were referred by healthcare providers to the study team, who explained the study and screened for eligibility. Eligibility criteria for PWE 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 PWE referred their primary support person. Eligibility criteria for PSP 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 occurs (0) to occurs most or all of the time (3). The CES-D is reliable and valid in general populations and in samples of PWE [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 minutes on average (range: 20 to 120 minutes) and were conducted over the phone by one of the researchers (ERW). Phone interviews were chosen to accommodate the transportation limitations experienced by PWE. PWE and PSP 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 PWE and PSP. 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 PWE. 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 PWE and 16 PSP) who represented 24 relationships (14 complete pairs, 8 additional PWE, and 2 additional PSP). The majority of participants were female (68%) and white (73%) (see Table 1). The average ages of PWE and PSP were 33.5 and 50 years, respectively. Most PWE were not working,

whereas the majority of PSP 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 Figure 1. The model shows how epilepsy impacts the lives of both PWE and PSP and how the experiences of PWE and PSP intertwine and influence one another. A brief definition of each section of the model is described below, followed by an explanation of the trajectories that PWE and PSP followed through the model.

3.2.1. Treatment Factors—All of the PWE were on medications to control their seizures. Six PWE found medications that reduced or stopped their seizures, while others tried numerous medications without finding one that was effective. PWE experienced various side effects including weight gain, bone density loss, cognitive impairments, and fatigue. Several PWE had brain surgery or a Vagus Nerve Stimulator (VNS) implanted in an attempt to control seizures that did not respond to medication.

3.2.2. Seizure factors—Most PWE began having seizures as children and had been living with epilepsy for many years (mean = 17.7 years). PWE experienced various types and severity of seizure (see Table 1). After a seizure, some PWE recovered easily, while others experienced headache, confusion, fatigue, or injury. PWE and PSP expressed fear and anxiety; for example, a woman with epilepsy stated, “So it’s kind of scary...when I’m having a major seizure and then I’m trapped in there, because you’re just kind of waiting, thinking what’s going to happen next?”

Despite the physical and emotional effects, seizures eventually became normalized into daily life, especially when epilepsy began in childhood. For some, seizures were never completely routine, although dealing with them became easier. A mother said, “I mean, when a seizure happens...it is traumatic. But then you pull yourself together and regroup, go see your doctor and increase meds, and you have a plan and you move on.”

3.2.3. Relationship Characteristics—The most common relationship between PWE and PSP was child-parent, followed by spousal. Other less common relationships included sibling, friend, and parent-child (see Table 1). Almost all of the PWE and PSP described being close to each other. The characteristics of a close relationship included open communication, being able to tell each other anything, and spending time together, though some PWE and PSP also experienced some “ups and downs” in their relationships.

3.2.4. Self-management—Self-management behaviors occurred across five domains: medication management (ex. taking medication as prescribed), trigger management (ex. reducing stress, getting enough sleep), symptom tracking and reporting (ex. keeping track of seizures and medication side-effects), treatment management (ex. attending doctor’s appointments), and information management (ex. gathering information about treatment and self-management). All of the PWE managed their epilepsy to some degree.

3.2.5. Support Provided—PSP provided a variety of support, including self-management, seizure, emotional, and instrumental support. PSP were involved to a varying degree in all aspects of the PWE's self management, ranging from supporting the PWE to performing management behaviors for them. Seizure support was provided before, during, and after seizures. Emotional support, which involved being there for the PWE, was very important to PWE. Instrumental support often included driving the PWE, supporting them financially, and, in the case of parents, giving their adult children a place to live.

3.2.6. Seizure Control—One-third of PWE had infrequent or fully controlled seizures. This level of control was achieved through effective medication, medication and trigger self-management, and, in one case, successful brain surgery. The other two-thirds of the PWE experienced uncontrolled and unpredictable seizures, despite good self-management and, in several cases, surgery or VNS implantation.

3.2.7. Illness Intrusiveness—Illness intrusiveness emerged as the main core category central to the model. Participants' descriptions of the impact of seizures on their lives aligned with the definition of illness intrusiveness, where valued activities and interests are disrupted by having an illness [1–3]. For PWE, the major domain of illness intrusiveness was independence, the ability to live life on their terms—including driving, holding a job, and going to school— without being overly reliant on other people. Some PWE were able to live independently; however others were dependent on PSP or were transitioning to independence. For PSP, illness intrusiveness manifested itself as the perceived burden of caring for the PWE.

3.2.8. Quality of Life—The level of illness intrusiveness experienced by PWE and PSP contributed to their quality of life. The emergent domains of PWE's quality of life centered on their outlook on life: living with disability, looking toward the future, or living life fully. For PSP, quality of life was characterized by their level of stress and mental well-being.

3.3. PWE Trajectories

PWE's paths through the model resolved into five main trajectories (see Table 2). Seizure control was a major factor in determining a PWE's trajectory because PWE with uncontrolled seizures experienced much higher illness intrusiveness compared to PWE with infrequent or controlled seizures. Other important factors included gender, time since diagnosis, the relationship type between the PWE and PSP, and patterns of support.

3.3.1. Trajectories 1–3: Uncontrolled seizures and high illness intrusiveness—

The PWE's epilepsy was uncontrolled in 15 pairs; these individuals had similar experiences with the intrusiveness of epilepsy in their lives, the limitations they faced because of seizures, and the support they received. These PWE could not drive, which restricted their ability to work or attend school. Seizures also affected cognitive processes or impaired memory, which inhibited their ability to complete tasks. Finally, necessary self-management routines (ex. getting enough rest) sometimes interfered with work or school schedules. As a result, PWE felt frustrated, disappointed, and guilty that they had to rely on others.

Three different patterns emerged based on the total amount of support received and the PWE's outlook on their life and expectations for the future. The reactions to illness intrusiveness and subsequent effects on the PWE's quality of life are discussed further under each trajectory.

3.3.1.1. Trajectory 1: Technically Disabled: The PWE in this group received an array of support, including support during and after seizures, support for self-management behaviors, instrumental support such as financial support and housing, and emotional support. Driving was the main limitation the PWE faced, along with an inability to work or go to school. Five of the PWE received Supplemental Security Income and Medicaid benefits and two PWE were either applying or planning to apply for disability benefits. One young woman described her situation:

Well I can't drive and I can't go nowhere, so I tell people I'm under house arrest... I can't get a job. So, with that I ended up getting disability because with Medicaid, because if I can't get a job, I can't get health insurance...I'm pretty much just stuck in the house.

The defining characteristic of the PWE in this group was a sense that their life was shaped by disability from their seizures. Seizures placed limitations on them and would continue to do so in the future. PWE, like the woman below, described feeling that aspects of their lives had been "taken away."

Actually, I don't work. I'm technically disabled. And so [seizures] hinder me. They actually, like, they rob me of a lot of my life... Things like that that most people take for granted...I'm not exposed to. So I feel robbed.

For PWE, particularly those who were diagnosed with epilepsy as adults, their disability challenged the roles they wanted to fulfill. One spouse said, "I want to get back out there and take care of my family but here I am, you know, on disability. This isn't what I want at all."

Conversely, a couple of PWE described acceptance of their condition, which allowed them to cope with the limitations of their life. This is illustrated by the following quote from a young man whose seizures had less of an emotional impact on him over time:

...it doesn't really upset me as much as it did because it's like an ongoing thing. You know it's going to happen. When it first started I would get really depressed and mad... But it's just, like, well, you know what it is.

Another couple stated that their faith helped them to cope with the wife's epilepsy. She said, "But I've come to the conclusion that this is the way the Lord's made me and there is a reason for it, and I just think it is up to him and he's going to take care of me through anything."

3.3.1.2. Trajectory 2: Trying to get back to normal: This group included two wife/husband pairs. Both women were diagnosed with epilepsy within the past three years and the dyads were still adjusting to the changes that seizures wrought in their lives. One woman said, "It's just been so hard on our family. And now, you know, it's like my whole family's

had epilepsy with me.” These women received support for their seizures and self-management.

The onset of epilepsy seriously altered the course of these women’s lives, resulting in the need to stop working. As they and their PSP struggled to come to terms with epilepsy, they both looked forward to an uncertain future and back toward what was a “normal” life. They hoped that the future would look like the pre-epilepsy past, as is illustrated by the following quote:

And I guess I’m just resigned, if that’s the right word, to everything... it’s affected our lives, my parents’ lives, and it’ll never be the same...we hope, the VNS will work to try to get back to a normal life. I still hope I can drive one day, you know?

3.3.1.3. Trajectory 3: Get out on her own: This trajectory included three daughter/parent pairs. These three women took the lead in managing their epilepsy, with reminders from PSP. PSP also provided instrumental support, mainly housing and financial assistance, and emotional support. Although these PWE faced similar limitations as the PWE in Trajectories 1 and 2, they expressed more frustration with the limitations on their independence and lives.

All three women were taking concrete steps toward being able to live independently, despite still experiencing seizures. Two women were looking for jobs with the hope of moving out on their own in the future, while the third woman was attending school. A job represented a way to decrease isolation, provide opportunities to socialize with other people, and demonstrate competence. To illustrate the last point, one woman stated, “I want to prove to people that I am capable of the things that they are as well.”

The PSP were very supportive of the PWE’s efforts to live independently and felt that it was an important step for these women to take. One father said,

It’s [epilepsy] right now forcing her to live under the roof of her father, which she shouldn’t have to be doing...she needs to have independence and she needs to have the standing on her own legs...

However, one mother acknowledged the fact that her daughter might not be able to live completely independently in the long run.

...all I ever wanted for her was to have a normal life and be able to do things that everybody else can do... I’ll always be there for her to fall back on if she wants to come back and live with me, but I just think it’s important for her to at least try, and she needs to be around other people her own age and that type of thing.

The PSP’s comments highlighted the importance for their daughters to live a “normal” life, in which children are expected to move out of their parents’ houses and become self-sufficient.

3.3.2. Trajectory 4: Moving into adulthood—This group was comprised of four son/mother pairs. The mothers provided a significant amount of support for self-management, as

well as emotional support, financial assistance, and housing. Overall, these young men relied on their mothers to a greater degree than the young women in Trajectory 3.

The mothers became involved in the PWE's care early in their lives because their sons were diagnosed with epilepsy during childhood or early adolescence and three of the young men had additional health conditions. Therefore, these patterns of support developed over time and perpetuated, even as the young men began transitioning toward adulthood. This transition involved the young men starting to take on more responsibility for their care and the mothers letting go of control over their sons' lives. One mother voiced a common hope:

Just that as [my son] does get older and become more independent that he will take on more responsibility, you know, for managing his own care. I don't mind doing it. It's not a burden to me. It's just the natural evolution of moving into adulthood.

The young men were taking steps toward living independently by living on their own, attending college, or working part-time. In describing moving into an apartment, one son said, "I lived with my parents for a little while so getting away from them was pretty nice... I mean I could just relax and not have like my parents looking over my shoulder the whole time." The mothers, however, continued to provide a high level of support by calling to remind them to take their medication, cooking meals, cleaning, and helping with school. The sons had mixed feelings about the support. For example, one son described his feelings about his mother's support by saying, "It's kind of a mixture of gratitude and, I don't know, mild disappointment in myself... I just like to be able to do it on my own, and right now I know I'm not."

3.3.3. Trajectory 5: How to be independent with this—The PWE in this group had infrequent seizures or were seizure free. They all lived independently or with their spouses and were the only PWE in this sample who worked full-time. Epilepsy intruded only minimally into their lives.

Self-management was a top priority for these PWE to prevent any future seizures and to keep their driving privileges. Being able to drive was crucial in order to maintain their independence, as illustrated by one man's statement that:

...the actual seizure doesn't bother me, what bothers me is losing my car, losing the ability to drive... And it's more the overall loss of independence, it's not the physical four wheels, because you become wholly dependent on other people to do for you, which is to me is a fate worse than death.

For the PWE with infrequent seizures, the periods without a license were characterized by loneliness, fewer social activities, and a greater reliance on others – a shrinking of their world. A woman described:

This last time was very frustrating because I needed milk and I can't just go get milk. But I don't want to call somebody to say hey can you take me to the grocery store to get one thing. You know and even though it's my family I still feel like I'm putting them out and you know I usually end up losing touch with a lot of friends for that six months or so...

The PWE in this group received mainly emotional support from their PSP, along with minimal self-management and seizure support. PSP were a “sounding board” and were “always there to listen.” For the PWE with infrequent seizures, their PSP’s support was instrumental to living independently, as is illustrated by the following quote by a daughter:

He went down the path of “you need to be responsible” and that “you need to take care of yourself... If you’re going to live on your own, you have to make sure that you take your medication...” Whenever I go and look for a place to live...I’m always on a bus line...so that I can make sure that I can get to work...

3.4. PSP Trajectories

Four distinct trajectories emerged for the ways in which PSP moved through the model (See Table 3). PSP experienced differences in the amount of support they provided to the PWE, the intrusiveness of that support and epilepsy in their lives, and the degree of stress and depressive symptoms they experienced. Seizure control and the PSP’s perceptions of the burden of support contributed to the illness intrusiveness of epilepsy. For most, the level of illness intrusiveness corresponded to the PSP’s quality of life, with high burden being associated with stress and low burden being associated with well-being. However, three PSP did not follow this pattern: two PSP experienced a high burden but low stress and one PSP with low illness intrusiveness had high depressive symptoms that were related to factors external to epilepsy.

3.4.1. Trajectory 1: Extraordinarily taxing—These PSP provided a high level of support to the PWE including emotional support, support for seizures, and help with management tasks. Other factors added to their caregiving burden, including stress from caring for other sick family members, financial instability, and pressure from work. The PSP experienced high illness intrusiveness due to the PWE’s seizures and the time, energy, and resources devoted to caring for them. To meet the PWE’s needs, the PSP gave up valued activities. A wife noted, “I’m limited in what I can do. I get off from work now, I have to come straight home...I don’t travel... I have to be conscious and aware that he’s home.”

Two main themes emerged that were related to the PSP’s perception of high burden of support: support falling solely on the PSP and support entailing more than the PSP expected. Five of the PSP in this group provided almost all of the support to their PWE. Other individuals were available to help on a limited basis, but while this support was helpful it did not substantively relieve the burden on the PSP. The extra support, when available, allowed the PWE’s care to be spread across multiple people, taking “a bit of the pressure off” the PSP.

The two spouses in this group experienced difficulties in adapting to a role that involved caring for a spouse who was significantly debilitated from seizures. One spouse noted that epilepsy is overwhelming and that “...I just didn’t realize what epilepsy entailed.” The spouses emphasized that the role of being a wife or husband and the love for their spouse were the reasons they provided the support. However, the alterations epilepsy wrought in their expectations for their lives and relationships added to their burden.

The PSP experienced poor mental health and well-being. The unpredictability of the PWE's seizures was stressful, and caring for the PWE during and after seizures made the PSP worried, anxious, or, in one case, distant. Providing support was a "marathon" that taxed PSP's resources and energy. Strikingly, all of the PSP in this group experienced elevated depressive symptoms (score of 16 or greater on the CES-D). All but one PSP, however, either said that they were not currently feeling depressed, or, if they did feel down or sad, said that they "wouldn't diagnose myself with depression." PSP expressed the need to fulfill caregiving and other responsibilities, to "push through it," despite their depression.

3.4.2. Trajectory 2: Limiting my time somewhere else—The two PSP in this group provided the majority of care to their PWE, who had uncontrolled seizures. Despite the high burden of support, both PSP maintained good mental health and low levels of stress. Both PSP chose to work less and spend more time caring for the PWE, thus reducing the demands on their time and their stress. A husband said:

...it can be a strain if you let it. And that's one of the reasons I retired as early as I did is that I thought it would be better for me to be here with her more, because at one time I was working 60 miles away from her and could not get home.

The mother described the benefits to the PWE, "I feel so strongly that it helped her so much by me limiting my time somewhere else and paying more attention, being focused and in tune with what she was going through."

The PSP acknowledged that providing support was still "time-consuming" and "tiring." They also found it stressful that they had no answers to what caused the PWE's seizures. However, these PSP seemed to achieve a greater balance compared to the PSP in Trajectory 1 who were overwhelmed by their support burden. One PSP said, "...we live a good life... we know our limitations, but we do most of what we want to do."

3.4.3. Trajectory 3: Not a burden—The PSP in this group provided emotional support, seizure support when needed, and assisted with self-management. Overall, they provided less support compared to the PSP in Trajectories 1 and 2 and experienced little illness intrusiveness. Providing support was not a stress, overwhelming, or an inconvenience; rather, the support was part of normal daily activities. These PSP felt that providing support was part of their role as a parent, spouse, daughter, or friend. According to a friend:

Really, the most important for me is to be there when [the PWE] needs my help and being just someone who he can talk to and, you know, letting him know that if he does have a seizure at the office, he is taken care of and just kind of taking that stress away from him. ...this is just part of what I've always done, and it's not really a hindrance or anything, it's just part of life.

Three PSP mentioned that additional support from spouses and friends was beneficial in both meeting the PWE's needs and their own need for emotional support. Another PSP described how her faith in God helped her to cope with her daughter's seizures. She said, "...if I start worrying about every little thing about it, it's going to drive me crazy, and I won't be able to take care of her. So, I've just got to have faith that God is going to keep her safe..."

3.4.4. Trajectory 4: Real-world life changes—The one father in this group provided emotional support to his daughter, whose seizures were controlled with medication (PWE Trajectory 5). He said, “I do get satisfaction that she’s taking care of herself, when she tells me she’s doing things...I feel good that she’s protecting herself and she’s moving on in life...” However, he described having poor mental health due to stress from work and financial difficulties.

4. Discussion

This study provides an exploratory, in-depth examination of how epilepsy affects the lives and experiences of adults with epilepsy and their PSP. In particular, we included the experiences and perspectives of the PSP because their voices are not well represented in the research literature. The findings and model demonstrate how the lives of PWE and PSP are intertwined, with epilepsy playing a large role in shaping quality of life.

The theme of illness intrusiveness figured prominently into our model, which aligned with and provides support for the Illness Intrusiveness Model [1–3]. Poochikian-Sarkissian and colleagues showed that seizure control was significantly and inversely associated with illness intrusiveness. They found that seizure freedom was also significantly associated with better health-related quality of life, positive affect, personal control, happiness, and self-esteem [2]. Our final model incorporated the main constructs of the Illness Intrusiveness Model, while extending it to include self-management, seizure control, support provided by PSP, the illness intrusiveness to PSP’s lives, and PSP’s quality of life.

Our findings provide insights into the associations between seizure control, illness intrusiveness, and quality of life. Seizure control was a main contributor to illness intrusiveness for both PWE and PSP. Similar to other studies [2, 47, 48], our results demonstrate how the degree of control and unpredictability of seizures contribute to feelings of anxiety, limit activities, and negatively affect quality of life. Illness intrusiveness was especially prominent in the lives of PWE with uncontrolled epilepsy; they experienced limitations to independence, driving, education and jobs, and relationships. These domains align with other research on the impact of epilepsy on the lives of PWE [6, 7, 49, 50].

Seizure control and illness intrusiveness played a large role, but did not completely determine the trajectories for PWE. Gender, relationships, and patterns of support were also associated with the PWE’s outlook and quality of life. PWE Trajectories 1 through 3 were influenced the most by seizure control and illness intrusiveness, either the disability imparted by uncontrolled seizures or the independence gained from infrequent or fully controlled seizures. The women in Trajectories 2 and 3 wanted to move toward independence, even though they experienced significant illness intrusiveness. The experiences of the daughters and sons in Trajectories 3 and 4 highlighted the desire of young adults to become independent from their parents, and the frustration that can result from not being able to be self-sufficient. This sentiment echoes results from focus groups conducted by Sample and colleagues [51] in which the theme of “having to be dependent on others” was particularly chafing for young adults.

Our study illustrates how PSP also experience illness intrusiveness, which is affected by both seizure control and the burden of providing support. PWE with uncontrolled seizures usually required a significant amount of various types of support. The uncontrolled nature of seizures also caused stress in PSP. Other researchers have also described lack of control as being stressful to PWE [15, 50, 52]. Similarly, Westphal-Guitti and colleagues [35] reported that caregivers of older adolescents and adults with epilepsy who reported high levels of burden also experienced role limitations due to emotional problems and poor mental health. However, seizure control did not entirely determine which trajectory PSP followed. Almost half of the PSP who experienced low burden and well-being (PSP Trajectory 3) supported PWE with uncontrolled seizures. In these cases, the PWE took the lead on managing their epilepsy, which relieved the overall burden of support for PSP.

Depressive symptoms figured prominently in the trajectories of some of the PSP, particularly among PSP who experienced a high level of burden. High caregiving burden is associated with poor mental health in epilepsy [35] and depressive symptoms in a variety of other conditions [53–55]. Nieboer and colleagues [55] reported that activity restriction is an important mediator between caregiving and depressive symptoms. In their study, not all caregivers experienced elevated depressive symptoms despite high caregiving burden. Similarly, the two PSP in Trajectory 2 reported a low level of depressive symptoms and described a good quality of life.

Another important theme across the PSP trajectories was the importance of support for the PSP. Most of the PSP who experienced high burden had little to no support for themselves, whereas many of the PSP who perceived a lower burden had people they could turn to. Support for PSP lightened their caregiving burden and provided needed emotional and instrumental support to the PSP. Higher levels of support for PSP is associated with lower depressive symptoms and positively affects quality of life [20, 33]. Our results support the recommendations by Mahrer-Imhof and colleagues [20] that PSP should be encouraged to share epilepsy management with PWE, share support tasks with other individuals, and cultivate relationships with family and friends.

4.1 Limitations

The results of this study should to be considered in light of several limitations. First, PWE who could identify a support person were recruited from a hospital-based, tertiary epilepsy clinic; they may experience more severe or complicated epilepsy compared to PWE who receive care from general neurologists or primary care physicians. Therefore, the experiences of PWE and PSP in this sample may not apply in different contexts. The goal of qualitative research, however, is not to generalize to a larger population, but to provide an in-depth view of participants' experiences [44, 45]. Second, we provided a description of a conceptual model drawn from the data, but cannot make claims of causation.

4.2. Implications and Future Research

Our model identifies pathways for future research on the health and well-being of PWE and PSP. This model and the trajectories can be empirically tested to determine how well they apply to a larger sample of PWE and PSP or to different disease conditions. Longitudinal

studies can shed light on causal relationships between the concepts in the model and explore how individuals proceed along trajectories and what factors might cause them to change trajectories. Factors of interest could include changes in relationships, coping mechanisms and routines established over time, or changes in seizure severity. Additionally, the model could inform the development of interventions to minimize illness intrusiveness and improve or maintain quality of life. Such programs should involve both PWE and PSP and could focus on maximizing PWE's independence, particularly for young adults, and extending the PWE's and PSP's support network.

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Highlights

- Epilepsy affects the lives of PWE and their support persons.
- We conducted qualitative interviews with PWE and support persons.
- We developed a dyadic model of living with epilepsy.
- Seizure control, relationship type, and gender shaped experiences of PWE.
- Seizure control, burden perceptions, and support shaped experiences of supporters.

Figure 1.
Dyadic model of living with epilepsy

Table 1

Demographic background of people with epilepsy and their primary support persons

	People with Epilepsy (n=22)	Primary Support Persons (n=16)
Age (years)		
Range	21–59	18–65
Mean (SD)	33.50 (9.78)	50.12 (12.65)
Gender, n (%)		
Female	15 (68.2)	11 (68.8)
Male	7 (31.8)	5 (31.3)
Race, n (%)		
African American	5 (22.7)	3 (20.0)
White	16 (72.7)	11 (73.3)
Other	1 (4.5)	1 (6.7)
Employment Status, n (%)		
Working	5 (22.7)	11 (68.8)
Unemployed	5 (22.7)	1 (6.3)
Student	3 (13.6)	-
Retired	1 (4.5)	4 (25.0)
On disability	6 (27.3)	-
Other	2 (9.1)	-
Depressive Symptoms		
No Depression (CES-D score <16)	12 (54.5)	9 (56.3)
Elevated Depressive Symptoms (CES-D score ≥ 16)	10 (45.5)	7 (43.8)
Seizures in the past 4 weeks		
Range	0–6	
Mean (SD)	1.76 (2.21)	
Years since Epilepsy Diagnosis		
Range	.3–39	
Mean (SD)	17.7 (9.22)	
Seizure Type ^a		
Generalized	17 (77.2)	
Partial	10 (45.4)	
Other	1 (4.5)	
Not sure	3 (13.6)	
Dyad Characteristics (n=24 relationships)		
Relationship (PWE/PSP), n (%)		
Daughter/Mother	6 (25.0)	
Daughter/Father	2 (8.3)	
Son/Mother	5 (20.8)	

	People with Epilepsy (n=22)	Primary Support Persons (n=16)
Wife/Husband	5 (20.8)	
Husband/Wife	2 (8.3)	
Sister/Brother	1 (4.2)	
Brother/Brother	1 (4.2)	
Mother/Daughter	1 (4.2)	
Friend/Friend	1 (4.2)	
Live in Same Household, n (%)		
Yes	20 (83.3)	
No	4 (16.7)	

Abbreviations: CES-D, Center for Epidemiological Studies Depression Scale; PWE, person with epilepsy; PSP, primary support person; SD, standard deviation

^a Some participants experienced more than one type of seizure, therefore the numbers and percentages for each category exceed n=22 and 100%, respectively.

Table 2

Trajectories through the dyadic model for people with epilepsy

Description	Characteristics
Trajectory 1: Technically disabled	
<ul style="list-style-type: none"> Uncontrolled seizures High illness intrusiveness Outlook of disability 	<ul style="list-style-type: none"> 10 pairs Variety of relationship types
Trajectory 2: Trying to get back to normal	
<ul style="list-style-type: none"> Uncontrolled seizures High illness intrusiveness Looking to “normal” life in the past Uncertain future 	<ul style="list-style-type: none"> 2 wife/husband pairs Diagnosed with epilepsy within past 3 years
Trajectory 3: On her own	
<ul style="list-style-type: none"> Uncontrolled seizures High illness intrusiveness Future plans to live independently 	<ul style="list-style-type: none"> 3 daughter/parent pairs
Trajectory 4: Moving to adulthood	
<ul style="list-style-type: none"> Uncontrolled seizures or seizure free Low to mid illness intrusiveness Transition to more independence 	<ul style="list-style-type: none"> 4 son/mother pairs
Trajectory 5: How to be independent with this	
<ul style="list-style-type: none"> Infrequent seizures or seizure free Low illness intrusiveness Living independently 	<ul style="list-style-type: none"> 5 pairs Variety of relationship types

Table 3

Trajectories through the dyadic model for primary support persons

Trajectory 1: Extraordinarily taxing	
• High illness intrusiveness	• 6 pairs
• High burden of support	• 2 spouse pairs, 4 child/parent pairs
• High depressive symptoms	
Trajectory 2: Limiting my time somewhere else	
• High burden of support	• 2 pairs
• Some stress	• 1 mother/daughter pair, 1 wife/husband pair
• Low depressive symptoms	
Trajectory 3: Not a burden	
• Low illness intrusiveness	• 7 pairs
• Low burden of support	• Variety of relationship types (4 child/mother pairs)
• Good mental health and well-being	
Trajectory 4: Real-world life changes	
• Low illness intrusiveness	• 1 father/daughter pair
• Low burden of support	
• High depressive symptoms	
• Stress from job	