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Perspectives of Adults With Epilepsy and Their Support Persons on Self-Management Support

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Abstract

Social support is an important mechanism for improving self-management, although little is known about its role in epilepsy self-management. We examined the type of support provided to people with epilepsy and its influence on self-management. We conducted in-depth interviews with 22 people with epilepsy and 16 support persons, representing 14 pairs and 10 unpaired individuals. We analyzed the data using principles of grounded theory. Supporters, who were mainly parents and spouses, aided people with epilepsy in every dimension of self-management. Support for self-management occurred along a continuum from person with epilepsy-led management to support person-led management. Where the pairs fell on the continuum depended on developmental stage, relationship type, and relationship dynamics. Seizure control shaped individuals’ experiences with self-management and support within each group. The self-management continuum provides a new aspect that can be integrated into existing models of self- and family-management.

Keywords
caregivers/caregiving; epilepsy; relationships; self-care; social support

People with chronic conditions must manage complex behaviors and practices to control their conditions, slow disease progression, and maintain quality of life (Clark, 2003; DiIorio, 1997). Self-management involves monitoring and managing symptoms, adhering to treatment and lifestyle regimens, and coping with the psychosocial stresses of living with a chronic condition (Barlow, Wright, Sheasby, Turner, & Hainsworth, 2002; Clark, 2003). Self-management behaviors, however, are not easy to implement and maintain. Up to 25% of individuals with chronic conditions report being nonadherent to medical...
recommendations, with higher rates of nonadherence for lifestyle changes, such as exercise and diet, compared with more specific and narrowly defined behaviors, such as taking medications (DiMatteo, 2004b). Nonadherence to self-management regimens is associated with increased symptom burden, greater functional disability, and higher health care utilization and costs (Osterberg & Blaschke, 2005).

Individuals report many barriers to managing their chronic conditions, including depression, low self-efficacy, physical limitations, poor communication with health care providers, lack of support, and financial burden (Bayliss, Ellis, & Steiner, 2007; DiMatteo, Lepper, & Croghan, 2000; Dunbar-Jacob & Mortimer-Stephens, 2001; Jerant, von Friederichs-Fitzwater, & Moore, 2005). Social support is one way to overcome these barriers and improve self-management. It has been associated with improved self-management outcomes for a variety of chronic conditions, including diabetes (Rosland et al., 2008; Schiotz, Bogelund, Almdal, Jensen, & Willaing, 2012), heart disease (Gallagher, Luttik, & Jaarsma, 2011; Sayers, Riegel, Pawlowski, Coyne, & Samaha, 2008), and epilepsy (Gallant, 2003). Social support can influence self-management by providing informational, instrumental, and emotional resources (DiMatteo, 2004a; Uchino, 2006).

Family members and close friends are in a key position to provide support to people with chronic conditions. Self-management behaviors, which often take place in a shared environment and in the context of relationships, naturally involve individuals beyond the patient (Rosland, 2009). In one survey, 75% of adults with diabetes or heart failure reported that family members were involved in their self-management (Rosland, Heisler, Choi, Silveira, & Piette, 2010). Support persons provide both general support, such as emotional support, and disease-specific support, including reminders for taking medication and going to doctor appointments (Gallant, Spitze, & Prohaska, 2007; Rosland, Heisler, & Piette, 2012). Support is associated with better self-management and health outcomes (Franks et al., 2006; Rosland et al., 2012), particularly when it is encouraging, enhances patient autonomy, or fosters family cohesion (Rosland et al., 2012). Conversely, support can lead to poorer self-management when it is critical, overprotective, nagging, or controlling (Bressi et al., 2007; Rosland et al., 2012; Trief, 2003).

The nature of the relationship between the supporter and the person with a chronic condition has an important influence on self-management. In a qualitative study on diabetes self-management, teamwork and helpful communication were identified as key elements of spouses working together (Trief, 2003). Poor communication, however, impedes self-management, can lead to conflict, and is associated with poorer health outcomes (Rosland et al., 2012; Trief, 2003). Additionally, supporters walk a fine line between providing needed assistance and infringing on the patient’s independence. Issues of independence emerge as key themes in qualitative studies; adults with chronic conditions feel strongly about being in charge of their self-management (Gallant et al., 2007; Trief, 2003).

Despite increasing evidence of supporters’ impact on an individual’s self-management, we identified two important gaps in the literature. First, the experiences of support persons are not often included. Researchers often quantitatively measure the support perceived by individuals with chronic conditions (Rosland et al., 2010; Rosland et al., 2012). Franks and
colleagues (2006), however, examined how spouses' reports of health-related support influenced patients' reports of health behaviors and mental health. Supporters are sometimes included in qualitative studies on chronic disease management (e.g., Tapp, 2004; Trief, 2003), though often the focus is on the support provided and offers few insights into how supporters feel about their role. Second, only a few disease conditions, mainly diabetes, heart disease, and arthritis, are represented in the literature. Study of other conditions can contribute to the understanding of experiences across chronic conditions. To address these gaps, we examined support for epilepsy self-management from the perspectives of both people with epilepsy and their primary support persons.

Epilepsy is a common neurological condition, affecting approximately 2.3 million Americans, that requires significant management to prevent seizures (Centers for Disease Control and Prevention, 2012). People with epilepsy must take medication, minimize exposure to seizure triggers, monitor symptoms and side effects, communicate with health care providers, and look for and process information about symptoms, management, and treatment (DiIorio, 1997). A substantial number of people with epilepsy are not consistently adherent in taking their medication, with 30-66% missing at least one dose in the past month (Hovinga et al., 2008; Paschal, Rush, & Sadler, 2013).

Support might be particularly important for improving people with epilepsy's self-management, although support needs are expected to vary depending on seizure type, severity, and triggers. The negative effects of seizures and medications, which include difficulties with memory and concentration (Fisher et al., 2000), might impede people with epilepsy's ability to manage their condition. Although there is little research on the support that people with epilepsy receive for self-management, some evidence indicates that primary support persons are involved in medication reminders and monitoring, supporting strategies for reducing stress and improving sleep, and providing instrumental and emotional support (Walker, Bamps, Burdett, Rothkopf, & DiIorio, 2012; Walker et al., 2014). People with epilepsy whose relatives show warmth report better medication adherence compared with people with epilepsy who receive criticism (Bressi et al., 2007). Additionally, support is associated with improved self-efficacy for self-management (DiIorio et al., 2004; Robinson et al., 2008).

The theoretical framework guiding this research was based on the social ecological model, Social Cognitive Theory (SCT), and theories of social support. The influence of factors outside the individual on health and behaviors are key aspects of the social ecological model and SCT. Support is an important component of the interpersonal level of the social ecological model and the environmental construct of SCT (Bandura, 1995, 2004; McLeroy, Bibeau, Steckler, & Glanz, 1988; Stokols, 1996). In theories of social support, support directly affects health by providing intimacy, companionship, and feelings of self-worth, and indirectly affects health by buffering the effects of stressors, such as living with a chronic condition (Cohen, Underwood, & Gottlieb, 2000; Heaney & Israel, 2008; Jetten, Haslam, Haslam, Dingle, & Jones, 2014). Based on these theories, we focused on the relationships between people with epilepsy and their primary support persons, the support provided to the person with epilepsy, and how these factors influenced the person with epilepsy's management of their condition.
To explore the role of support in self-management we used qualitative methods to answer two research questions. What types of support for self-management do people with epilepsy receive from their primary supporters? How do primary support persons influence people with epilepsy’s self-management?

Methods

Design and Study Procedures

This study draws on the qualitative portion of a sequential mixed methods study that included a quantitative phase followed by a qualitative phase. The purpose of the overall mixed-methods study was to examine the interpersonal relationships between people with epilepsy and their support persons, and the effect of these relationships on self-management and mental health. The qualitative phase, based on grounded theory, allowed for an in-depth examination of the experiences of people with epilepsy and their supporters, as told in their own words, and provided context for the quantitative results (Creswell & Clark, 2007).

Additional detail about the mixed methods design has been published elsewhere (Walker et al., 2014). For this article, we focused specifically on the qualitative data on support for epilepsy self-management.

People with epilepsy were recruited from a hospital-based epilepsy clinic between April and November 2011. Patients were eligible if they were 18 or older, had a diagnosis of epilepsy for at least three months, could identify a primary support person, and spoke and read English. Eligible individuals referred their primary supporter, who was defined as a nonpaid individual who provided or would be most likely to provide support to the person with epilepsy. Eligibility criteria for primary support persons included: being 18 or older, providing unpaid assistance to a person with epilepsy, and speaking and reading English. People were not eligible if they did not have the cognitive ability to independently provide consent. Health care providers at the epilepsy clinic informed patients about the study and referred interested patients to the research team. One researcher (first author) explained the study in detail, determined eligibility, and obtained written informed consent. Emory University’s Institutional Review Board approved all study procedures.

Data Collection

For the quantitative phase, all participants completed a short survey over the phone. The survey assessed self-management, support for self-management, emotional support, depressive symptoms, quality of life, and demographic characteristics. After completing the survey, we conducted in-depth semi-structured interviews with a subset of participants for the qualitative phase. We expected that epilepsy experiences, self-management, and support would vary across dyads because of the condition’s heterogeneous nature. Therefore, we used purposive sampling to capture information across a diverse and information-rich sample (Patton, 2002). Individuals were selected to represent diversity in relationship type, gender, race/ethnicity, self-management, support, and depressive symptoms. Participants’ scores from the survey were used to help identify those who could provide a variety of viewpoints.
People with epilepsy and supporters independently completed semi-structured phone interviews with the first author that lasted, on average, 45 minutes. Data collection by phone was chosen because people with epilepsy often experience transportation limitations: They cannot legally drive in the state of Georgia if they have had a seizure within the past six months (Epilepsy Foundation, 2012). Phone interviewing yields quality data on par with data gathered from face-to-face interviews (Novick, 2008; Sturges & Hanrahan, 2004). Participants received a $25 gift card to compensate them for their time.

The semistructured interview guide was developed, based on the literature, the theoretical framework, and research questions, to capture five domains: experiences with epilepsy, effects of epilepsy on the lives and relationships of people with epilepsy and their supporters, characteristics of their interpersonal relationship, support provided to the people with epilepsy, and support specifically for self-management. Parallel questions were asked of people with epilepsy and their support providers. For example, people with epilepsy were asked, “How does [support person] help you with managing your epilepsy?” whereas supporters were asked, “What do you do to help [person with epilepsy] manage his/her epilepsy?” Probes were used to prompt the participants for additional information, examples, or deeper explanation. All interviews were audio-recorded, de-identified, and labeled with a unique identification number, then transcribed verbatim by a professional transcriptionist. The first author reviewed all transcripts with the audio to ensure accuracy and to deepen familiarity with the narratives.

Data Analysis

Grounded theory methods, arising from both pragmatism and symbolic interactionism, were originally devised by Glaser and Strauss (1967) as a systematic method of analyzing qualitative data to build theory (Corbin & Strauss, 2008) or extend theory (Snow, 2004). We used a modified grounded theory approach to allow us to extend our theoretical framework, rather than simply provide description. Data analysis was initiated during data collection, which allowed us to further refine the interview guide based on emerging themes (e.g., adding a question about the effect of epilepsy on the supporter’s life).

We developed a codebook through both deductive and inductive approaches. First, we developed a list of a priori codes based on the broad domains of the interview guide derived from the theoretical framework. Although this approach differs from traditional grounded theory, we wanted to incorporate important concepts from the framework into the analysis (e.g., types of social support). Then, the first and second authors independently coded six transcripts by applying the a priori codes and via open coding, which involved adding codes that identified new concepts and themes relevant to the research questions (Corbin & Strauss, 2008). To ensure intercoder reliability, two researchers (the first author and the second or third authors) independently coded all transcripts. After approximately every six to 10 transcripts, the researchers met to discuss the coding, address any discrepancies, adjust the codebook, and recode transcripts as necessary.

The first round of coding and comparisons of all interviews were completed by hand. Subsequently, we employed the qualitative software package MAXQDA (VERBI Software, 1989-2014) for data management and coding. The constant comparative method was used to
ensure that each segment of text fit within the code and to identify dimensions of the code (Boeije, 2002; Corbin & Strauss, 2008). As coding progressed, relationships between codes were delineated through axial coding. We wrote analytic memos throughout the process to explore the relationships between themes. We found that the a priori codes allowed us to organize data around more concrete concepts (e.g., types of self-management and support), whereas the inductive codes captured more nuanced or abstract concepts (e.g., burden, ambivalence, independence). For this article, we focused on the categories of self-management, support for self-management, relationships, and seizure control and the five to eight subcodes specifically related to each of these main themes.

Results

A total of 38 individuals completed in-depth interviews (22 people with epilepsy and 16 primary support persons). These participants represented 24 relationships—14 complete pairs, eight additional people with epilepsy, and two additional supporters. Overall, the majority of participants were women, White, lived with family, and completed at least some college (see Table 1). Most people with epilepsy were single and not working, whereas most support persons were married and worked full-time. Primary supporters most commonly were the parents or spouses of the people with epilepsy. The majority of people with epilepsy had uncontrolled seizures. Several achieved some control through medication but experienced infrequent seizures, and four individuals had complete seizure control.

Patterns of self-management and support revealed that relationship type, relationship dynamics, seizure control, and perceptions of support were important themes. We first give an overall description of self-management and support for self-management, followed by an in-depth look at patterns of support based on the degree to which primary support people were involved in managing epilepsy.

Self-management Behaviors

All the people with epilepsy managed their condition to some degree. The self-management behaviors fell within the five main categories of epilepsy self-management: medication, trigger, symptom tracking and reporting, treatment, and information (see Table 2). All the people with epilepsy were taking anti-epileptic medications. Most individuals had a routine for taking daily medication, though this routine often altered when traveling or when deciding to take as-needed medication before or after a seizure. Almost all the people with epilepsy also tried to reduce their exposure to seizure triggers, whether they knew what caused their seizures or not. All the people with epilepsy met regularly with their neurologist to monitor seizures and medications. Less commonly, people with epilepsy kept a log of when their seizures occurred to inform neurologists about frequency and severity and aid in identifying possible triggers. A few people with epilepsy also said they search for information to learn more and keep updated on new treatments.

Self-management Support

Support persons aided people with epilepsy across all five categories of epilepsy self-management (see Table 2). Two main roles for the supporter emerged from the participants’
interviews: management assistance and direct management. Management assistance involved helping as the person with epilepsy managed his or her epilepsy. In this capacity, supporters reminded people with epilepsy about various self-management tasks, monitored people with epilepsy to make sure they took medication, and tracked when seizures occurred. Direct management involved support persons performing self-management tasks for the person with epilepsy. Examples of direct management included calling in and picking up medication refills and making doctors’ appointments. In addition to the two management-specific roles, support providers also offered emotional support to people with epilepsy to encourage their self-management and help them cope with the stresses of living with epilepsy.

**Self-management Continuum**

The primary support persons’ involvement in epilepsy management spanned a continuum from person with epilepsy-led management, to joint management, to supporter-led management. Figure 1 displays where each pair fell on the self-management continuum. To determine this placement, we examined participants’ comments related to self-management and support, and assessed which dyad member took the lead and to what degree. Most of the pairs fell on the person with epilepsy-led side of the continuum, though almost a third were on the support person-led side. Three pairs fell under joint management. Next we examined codes and concepts that might have contributed to the groupings of the pairs. Influential factors included developmental stage, relationship type, and relationship dynamics. Degree of seizure control was not a determining factor in a pair’s location along the continuum, but it was important in shaping experiences within each group. Below, we describe the patterns of self-management support and the positive and negative aspects of receiving and providing support.

**Person with epilepsy-led management**—In person with epilepsy-led management, that person was primarily responsible for his/her self-management and the supporter provided assistance as needed or wanted. Thirteen pairs were classified under person with epilepsy-led management, representing a variety of relationship types, including almost all the daughter/parent and wife/husband pairs. For 11 of these pairs, in which the people with epilepsy had infrequent to uncontrolled seizures, the main role of the support person was “to have your back.” In the remaining two pairs, the people with epilepsy were almost completely self-reliant in managing their epilepsy.

**Have your back**—Women made up the majority of the people with epilepsy in this group; the two men were the only men to have male supporters. The people with epilepsy in this group did not have fully controlled seizures; a few had infrequent seizures, but most had frequent and unpredictable seizures. All these people with epilepsy took their medication as prescribed and avoided seizure triggers. Several individuals also kept a log of when they had seizures or searched for information about epilepsy.

This group received fairly minimal but consistent management assistance. This support involved reminders about trigger management and/or medication taking, often when the people with epilepsy were in nonroutine situations. The primary support persons’ assistance
was a reinforcement to the people with epilepsy's daily routine of self-management. Several people with epilepsy mentioned that the supporters “have [their] back” in making sure they did what was needed to manage their epilepsy. The support persons described stepping in if they saw the people with epilepsy not performing a necessary self-management behavior. A mother said:

… one of the biggest things now is her sleeping, not getting enough sleep, and because if that gets out of control, then that'll cause more seizures … If I see that she's forgetting to do something, that's when I'll step in, but for the most part, I try to let her do everything herself.

Particularly in the case of daughters with epilepsy and their parents, the supporters noted that the daughters took on more responsibility for their management as they transitioned from adolescence to adulthood. As these women took a larger role in their self-management, the parents stepped back into a more supportive role.

The people with epilepsy described both positive and negative reactions to the support they received. They were thankful for both the self-management and emotional support from their support persons. However, reminders from support persons could also be frustrating and annoying, particularly when the people with epilepsy were about to or had already completed a particular self-management task when the supporters offered a reminder. This reaction was common among young adult women responding to their mothers, as in the quote below.

It can just get annoying sometimes. ‘Do this, do this,’ and I'm thinking, I'm going to do it and I'm going to do it right now soon. So, you don't need to bug me about it. I'm thirty-two years old, just calm down a little.

Some people with epilepsy, particularly those who had uncontrolled seizures, felt frustrated that they were not more independent of their support person. As one woman said,

Sometimes it makes me feel … as if I'm being doubted as far as my competency of doing certain tasks. I know she's trying to be helpful and remind me of certain things, but sometimes it gets to me as far as making me feel as if I'm too dependent on her and I'm incapable of being on my own.

The supporters did not express the same frustrations with providing reminders and assistance; they were “not inconvenienced” and did not find the support to be a “chore” or “a big deal.” They viewed the support they provided as part of their role as a parent, daughter, or friend. In the words of one father, “I'm helping out somebody I love and that's important. She's really the only vestige of family I have around and I guess that's important.”

For support persons, the main benefits from providing support were the satisfaction of helping and showing their love.

Self-reliance—The two pairs in this group experienced support differently than the other pairs who fell under person with epilepsy-led management. Both women's seizures were completely controlled, allowing them to be self-sufficient, live on their own, and work full-time. They also spent less time with their support persons on a daily basis compared with the other people with epilepsy in this sample.
Both women managed their epilepsy carefully by taking their medication, getting enough sleep, eating right, and minimizing stress. Although they received occasional reminders from their supporters to take their medication, they mostly received emotional support. One woman with epilepsy said of her brother, “I know he’s always going to be there.” A daughter with epilepsy said, “I don't feel like I'm alone. I think that's probably most important.”

**Joint management**—Three pairs of spouses worked together to jointly manage epilepsy. These pairs often used the pronoun “we” when discussing self-management activities and one wife described herself and her husband as a “team.” Additionally, all the people with epilepsy stated that communication was an important element of the relationship.

The supporters engaged in a combination of management assistance and direct management related to medication, triggers, and doctors' appointments. One husband said,

> Well I try to ensure that she gets proper sleep, proper rest, not to overdo herself, not to worry. Have you taken your medicine this morning, have you taken it this afternoon? You know, do we need to talk, what's on your mind, are you concerned about something? You know, I try to stay engaged with her to make sure that she's not overly worrying or concerned about things.

All the couples said emotional support was an important element of the overall package of support provided.

The experiences of providing and receiving support varied, depending on seizure control, and involved both positive and negative emotions and reactions. For the one pair in which the husband's epilepsy was controlled, self-management was complicated by comorbid diabetes. He described how his wife helped him manage both conditions:

> Cooking right and making sure I'm taking the medicine. She'll just go behind me and makes sure I'm taking it. Makes sure I'm getting the refills and she calls the refills in sometimes … And she walk with me too some.

The husband felt that it was good to have her “checking up” on him; however, he also made sure to take his medication so that she did not “nag” him. From the wife's point of view, providing support was a way to show how much she cared and was not a burden to her. She said, “It all has blended in with daily life. It don't stress me out. It don't get to me.”

The other two couples dealt with uncontrolled seizures. The members of both pairs were active in medication and trigger management. Benefits of support included improved self-management by ensuring that medication was being taken properly and identification of seizure triggers. A wife said:

> … sometimes we try to figure out stuff and see what may have, like I said, triggered something. And most of the time we can take it back, you know, to something that may have happened or if, you know, I forgot to take medicine, something like that.
Both people with epilepsy were grateful for the support from their spouses. The husband with epilepsy appreciated his wife's support, though it bothered him to see the burden on her.

How thankful I am that God provided me with somebody that he knew I was going to need and that has the heart to do this … It has its plusses and weaknesses at times. We all get tired and she gets tired, not only with me, but her job … So that's hard on me to see her being tired about anything and can't step up to the plate and just take care of it because of this unfortunate illness.

His wife said, “So it's solely on me because our daughter is at college. It gets tiring at times. I feel frustrated.” The strain of being the only person to provide support was also difficult for the husband of a woman with uncontrolled seizures, who said, “Well sometimes you feel alone, you know. You're the only one that's doing it … she doesn't want to be a burden on anybody, and, you know, she and I have an agreement that I'm it.” However, for both spouses, providing support was seen as part of their role as “being a good wife” or husband.

**Primary support person-led management**—In primary support person-led management, supporters directly managed their person with epilepsy's condition. Two reasons emerged for why the support person had primary responsibility for management. One reason was related to relationship type and developmental stage and the other to seizure control. The first group included four young adult sons with epilepsy and their mothers, who were negotiating the sons' transition to adulthood. This process involved the sons taking on more independence and the mothers “letting go.” The second group included four pairs, with a variety of relationship types, in which the people with epilepsy were “essentially incapacitated” by uncontrolled seizures.

**Stepping up and letting go**—In this group, the four young adult men started having seizures as children; therefore, their mothers' supportive behaviors developed over a long period of time, starting when the mothers needed to do most of the managing. It became normal and routine for them to continue managing their sons' epilepsy. One mother said,

Because this all began at an age when, you know, for the most part, I managed his entire life … he has a heart condition also. Between the heart and the seizures, you know, there's been a lot of doctors … it just feels like what a parent would do. It feels completely normal.

Similar to supporters in the other groups, these women felt that providing support was part of their role as a mother.

The sons, whose ages ranged from 18-24, were in the process of transitioning from late adolescence to independent adulthood. They wanted to live on their own and find steady employment, although they relied on their parents for financial support and housing. While grateful for their mothers' support, they also felt frustrated because “it kind of doesn't let me be on my own.” The mothers also wanted to see their sons live independently. However, these mothers continued to directly manage their sons' epilepsy because that is what they had always done and because they felt the sons would not do it themselves. One mother said,
But I’ve felt like I’ve had to do things, like remind him to take his medicine, put his medicine, be sure he gets his medicine, make his doctor's appointments. You know, he's never shown an initiative to do any of that on his own … He wants to be independent, but you've got to show me that you can, and you can't expect to be independent if I'm still paying for everything.

As we describe below, the mothers seemed to be waiting for their sons to take the lead on their epilepsy management before relinquishing that responsibility to them.

He's not an advocate for himself, and that's one thing I'm working on because, you know, I'm his advocate. And I want him to be his own advocate and so, you know, we're kind of working on that … It's hard. I mean, I need to let go and he needs to step up.

Essentially incapacitated—The four people with epilepsy in this group experienced uncontrolled and severe seizures that impeded their ability to perform self-management behaviors on their own. These individuals described lingering effects (e.g. tiredness, confusion) and long-term effects (e.g., memory difficulties) from their seizures. Although the people with epilepsy were involved in self-management, the support persons took on the main role. For example, one husband said,

I control all of her medications and her medication schedules. I'm the one making and taking her to all of her appointments; she can't even do a good job of describing her overall situation with her doctor because she doesn't know. She's like, “I can talk to my doctors,” but I'm like, “You can't, because you will say that you were fine yesterday and you don't remember yesterday.”

All the people with epilepsy expressed conflicting emotions regarding the level of assistance from their supporters. On the positive side, they felt grateful for the support, which allowed them to stick to a self-management regimen. On the negative side, it was difficult to have someone else be in such control over their lives.

I get aggravated because [my mother is] always around, helping me, and I just want to do everything on my own. But I understand that I can't now, and she's there for me. But, yeah, I get aggravated sometimes. I get tired of her always helping me, but I know it will get better.

Only two of the supporters in this group completed interviews: a mother and a husband. They experienced a heavy burden of caregiving, both because of the epilepsy management tasks they performed and the need to constantly monitor and help their person with epilepsy in case of a seizure. The mother, whose daughter was diagnosed with epilepsy 11 years ago, said that providing support can be “strenuous.”

But being my daughter of course, I'm very, very happy to be able to do that. And it's time-consuming, but I consider it like, um, I don't mean this to sound in a bad way but kinda like a job. But I, you know, just plan on that's how I'm going to spend my time …
In the husband's case, his wife was recently diagnosed with epilepsy; thus in addition to providing care he was also adjusting to an unexpected change in their roles in the relationship.

I get the sickness and in health thing, and it's just, I don't want any part of this … I wouldn't shirk my responsibilities, because I take it very seriously, because I love her, but this is not what I signed up for. This is extraordinarily taxing on me.

Both support persons viewed the support they provided as part of their role as a mother and husband, despite the time, energy, and stress involved.

Discussion

We examined the perceptions of people with epilepsy and their primary support persons regarding the types of self-management support received and provided and how that support influenced self-management. Epilepsy provides an example of perceptions and factors that are important to support for self-management of chronic conditions. The participants' experiences clearly show that the person with a chronic condition rarely undertakes self-management completely on his or her own; rather, in many cases, the support person is directly involved in management. The self-management continuum in Figure 1 represents the differing levels of support that people with epilepsy receive. Important factors that influenced placement along the continuum included relationship type and developmental stage. Two other important themes that shaped experiences of support for self-management were seizure control and perceptions of the support persons' role.

A clear gender divide emerged along the continuum. Most of the women, particularly daughters, fell under person with epilepsy-led management unless they experienced severe impairment from seizures. Conversely, all the sons fell under primary supporter-led management. The gender differences for adult children with epilepsy appear to be influenced by the transition into adulthood. Daughters were further along the transition to adulthood compared to sons. The expectation of both daughters and their parents was that the daughters held primary responsibility for their epilepsy self-management. In contrast, the sons and their mothers were negotiating a process by which the sons would take on more responsibility and the mothers would let go of their control. One possible explanation for this is that the daughters were, on average, slightly older than the sons. Alternatively, parents might expect daughters to take on responsibility earlier than sons.

Literature on the transition to adulthood for adolescents with epilepsy or their families is scarce, particularly regarding the transfer of control over self-management behaviors. Research on other chronic conditions, such as diabetes and congenital heart disease, suggests that parents can help or hinder the adolescents or young adults in assuming independence and responsibility for their health. Parents play a key role in fostering autonomy in their children, which can be necessary for successful self-management (Hanna, 2012; Sable et al., 2011). Additional research is needed to understand this process and the long-term implications for self-management and health outcomes for young adults with epilepsy.
There was variation in the location of spouse pairs along the self-management continuum and spouse pairs were the only relationship type represented in joint management. Spouses might be more likely to adopt a “team” approach to management because the partners tend to be on equal footing, compared with the hierarchy of a child/parent relationship, and live closely together, compared to the siblings or friends. As part of this closeness, spouses developed and maintained a series of routines that balanced management activities with everyday tasks (Corbin & Strauss, 1988). Although parents and their adult children with epilepsy also had established routines, there was an expectation that eventually the adult child would gain further independence. The spouses, however, developed their routines together over time, and expected to continue to do so into the future.

A theme that emerged across the continuum was that providing support was an integral part of the support persons’ role as parents, spouses, or friends. Supporters’ emotions around this role varied; some accepted this role and were content, others felt obligated to care for the person with epilepsy, and a few individuals struggled with adapting to a caregiving role. Becoming a caregiver can be overwhelming, as responsibilities increase and relationships shift, and can have negative effects on the mental health and quality of life of both the caregiver and care recipient (Plank, Mazzoni, & Cavada, 2012; Rees, O’Boyle, & MacDonagh, 2001; Westphal-Guitti et al., 2007). Therefore, support persons might be most vulnerable to poor health outcomes if life changes cause the pair to move suddenly to primary support person-led management. Mental health assessment of both dyad members by health professionals, as well as opportunities to acquire coping skills, might be helpful in allowing the support person to adapt to changes in his/her role.

Seizure control was not a determining factor in where pairs fell on the self-management continuum, although seizure control did shape experiences within each grouping. The goal of self-management for people with epilepsy is seizure control. However, faithfully maintaining a self-management regimen does not ensure a reduction in seizures and about a third of individuals continue to experience uncontrolled seizures (Devinsky, 1999). In the current study, almost all the people with epilepsy had uncontrolled seizures, despite high levels of self-management. Therefore, support might help the people with epilepsy to maintain their self-management routines, but might not have a large impact on seizure control. Poor seizure control might not prevent the completion of self-management tasks, as is evidenced by the large proportion of people with uncontrolled seizures in the person with epilepsy-led management group. Additional research is needed to determine if these patterns are replicated in the broader epilepsy population and to quantify the effects of seizure control on a person’s ability to manage his or her epilepsy.

The interviews provided a snapshot into where the pairs fell along the self-management continuum at one point in time. However, several factors could cause dyads to move along the continuum. First, a worsening of seizure control could cause a person with epilepsy to rely more heavily on the supporter, whereas improved seizure control could result in the person with epilepsy taking the lead on his or her self-management. Second, as young adult children transition into adulthood, they might assume more responsibility for their management. Finally, changes in who is providing support could lead to movement along the continuum as new self-management routines are negotiated and established. Additional
research is needed to determine when and how movement along the continuum occurs and the impact on overall self-management. By periodically assessing a dyad's placement on the continuum, health and social service professionals could identify when changes in the support person's role occurs and facilitate discussion around establishing workable self-management routines.

The self-management continuum can extend our theoretical framework, which drew on the interpersonal interactions found in the social ecological model, Social Cognitive Theory, and models of social support. Our results demonstrate that in addition to helping people with epilepsy complete their self-management behaviors, which is represented in the theoretical framework, the support persons often directly manage epilepsy as well. This direct management can occur even when the person with epilepsy is not incapacitated; thus, our findings offer insights into the factors that contribute to how self-management behaviors are completed and by whom. Several relevant models of self- and family-management of chronic conditions depict the factors affecting management and the outcomes for both patients and families. These models assume that chronic disease management is a dynamic process requiring both individuals and families to incorporate health-related behaviors into their daily lives (Dunbar, Clark, Quinn, Gary, & Kaslow, 2008; Grey, Knafl, & McCorkle, 2006; Ryan & Sawin, 2009).

Our results also highlight the multifaceted nature of social support, including amount and types of support, as well as positive and negative aspects of support. The complexity of this concept is apparent in theories of social support. Researchers historically have had difficulty drawing all the facets into a succinct model (Langford, Bowsher, Maloney, & Lillis, 1997). The continuum figure depicts how the support person's role varies from minimal involvement to directly taking on management tasks. These levels of support are often not captured in measures of social support, which can lead to an incomplete picture of how self-management is fully accomplished. A practical implication of our results is that health and social service professionals must take into account the dynamics between both the person with epilepsy and the support provider. Future research should further examine the effects of location on the continuum on self-management and treatment outcomes.

**Limitations**

Although every effort was made to interview both members of the dyad, it was not always possible to contact, receive informed consent from, or schedule interviews with both people. Interviews with individuals whose pair member did not participate still provided rich information; however, the ability to compare perspectives on shared experiences and relationships was lost. This study focused on individuals and their primary support persons; therefore the perspectives of other supportive individuals, who also can be instrumental in a person with epilepsy's self-management, were not included. Additionally, people with epilepsy who did not have a supporter were excluded from the study. Future research should examine the influence of a patient's entire support system, or lack thereof, on self-management. Finally, patients were recruited from a tertiary epilepsy clinic; therefore they might experience more severe or intractable seizures compared with people with epilepsy in the general population.
Implications

This study has implications for theory, research, and practice. First, the self-management continuum can be integrated into existing models of self- and family-management and applied to other chronic conditions. Future research could determine the extent to which the continuum works for other conditions and the disease-specific factors that contribute to a dyad’s location on the continuum. Second, these results indicate the need for developing a measure that takes into account the management behaviors undertaken by the support person. Such a scale could locate dyads and provide the basis for assessing different support needs along the continuum. Finally, given the central role of supporters in helping many patients manage their condition, health care providers, self-management programs, and support groups should involve support persons and facilitate discussion about desired and optimal support for the patient. These conversations should involve aspects of life beyond the chronic illness that affect self-management, such as a young adult’s transition to becoming an autonomous adult and changes in the caregiving role.

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References


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Figure 1. Self-management continuum of person with epilepsy and support person pairs
### Table 1
Demographic Characteristics of Interview Participants (n=38)

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>People with Epilepsy (n=22)</th>
<th>Primary Support Persons (n=16)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Relationship, n (%)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Adult Child</td>
<td>11 (50.0)</td>
<td>1 (6.3)</td>
</tr>
<tr>
<td>Parent</td>
<td>1 (4.5)</td>
<td>10 (62.5)</td>
</tr>
<tr>
<td>Spouse</td>
<td>7 (31.8)</td>
<td>4 (25.0)</td>
</tr>
<tr>
<td>Sibling</td>
<td>2 (9.1)</td>
<td>-</td>
</tr>
<tr>
<td>Friend</td>
<td>1 (4.5)</td>
<td>1 (6.3)</td>
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<tr>
<td><strong>Gender, n (%)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Women</td>
<td>15 (68.2)</td>
<td>11 (68.8)</td>
</tr>
<tr>
<td>Men</td>
<td>7 (31.8)</td>
<td>5 (31.3)</td>
</tr>
<tr>
<td><strong>Race, n (%)</strong></td>
<td></td>
<td></td>
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<tr>
<td>African American</td>
<td>5 (22.7)</td>
<td>3 (20.0)</td>
</tr>
<tr>
<td>White</td>
<td>16 (72.7)</td>
<td>11 (73.3)</td>
</tr>
<tr>
<td>Other</td>
<td>1 (4.5)</td>
<td>1 (6.7)</td>
</tr>
<tr>
<td><strong>Marital status, n (%)</strong></td>
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<tr>
<td>Married</td>
<td>6 (27.3)</td>
<td>10 (62.5)</td>
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<tr>
<td>Single</td>
<td>13 (59.1)</td>
<td>3 (18.8)</td>
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<tr>
<td>Separated/divorced/widowed</td>
<td>3 (13.5)</td>
<td>3 (18.8)</td>
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<tr>
<td><strong>Living Situation</strong></td>
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<tr>
<td>Alone</td>
<td>3 (13.6)</td>
<td>1 (6.3)</td>
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<tr>
<td>Immediate family</td>
<td>17 (77.3)</td>
<td>15 (93.8)</td>
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<tr>
<td>Friend, roommate, partner</td>
<td>2 (9.1)</td>
<td>-</td>
</tr>
<tr>
<td><strong>Education</strong></td>
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<td></td>
</tr>
<tr>
<td>High school or less</td>
<td>5 (22.7)</td>
<td>2 (12.5)</td>
</tr>
<tr>
<td>Some college or currently in college</td>
<td>7 (31.8)</td>
<td>1 (6.3)</td>
</tr>
<tr>
<td>Graduated college or higher</td>
<td>8 (33.5)</td>
<td>12 (75.1)</td>
</tr>
<tr>
<td>Other program (e.g. technical)</td>
<td>2 (9.1)</td>
<td>1 (6.3)</td>
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<tr>
<td><strong>Employment Status, n (%)</strong></td>
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<tr>
<td>Full-time</td>
<td>5 (22.7)</td>
<td>9 (56.3)</td>
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<tr>
<td>Part-time</td>
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<tr>
<td>Student</td>
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<td>Retired</td>
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<td>Unemployed</td>
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<tr>
<td>On disability</td>
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<tr>
<td>Other</td>
<td>2 (9.1)</td>
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<tr>
<td><strong>Age (years)</strong></td>
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<td></td>
</tr>
<tr>
<td>Range</td>
<td>21-59</td>
<td>18-65</td>
</tr>
<tr>
<td>Characteristics</td>
<td>People with Epilepsy (n=22)</td>
<td>Primary Support Persons (n=16)</td>
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<tr>
<td>---------------------------------</td>
<td>-----------------------------</td>
<td>-------------------------------</td>
</tr>
<tr>
<td>Mean (SD)</td>
<td>33.50 (9.78)</td>
<td>50.12 (12.65)</td>
</tr>
<tr>
<td>Seizures in the past 4 weeks</td>
<td></td>
<td></td>
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<tr>
<td>Range</td>
<td>0-6</td>
<td>-</td>
</tr>
<tr>
<td>Mean (SD)</td>
<td>1.76 (2.21)</td>
<td>-</td>
</tr>
<tr>
<td>Years since epilepsy diagnosis</td>
<td></td>
<td></td>
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<tr>
<td>Range</td>
<td>3-39</td>
<td></td>
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<tr>
<td>Mean (SD)</td>
<td>17.7 (9.22)</td>
<td></td>
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<tr>
<td>Self-management categories</td>
<td>Person with epilepsy – self-management</td>
<td>Support person – management assistance</td>
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<tr>
<td>---------------------------------</td>
<td>----------------------------------------</td>
<td>----------------------------------------</td>
</tr>
<tr>
<td>Medication management</td>
<td>Reminders (e.g. alarm)</td>
<td>Reminders</td>
</tr>
<tr>
<td></td>
<td>Filling pillbox</td>
<td>Monitoring</td>
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<tr>
<td></td>
<td>Refills</td>
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<tr>
<td>Trigger management</td>
<td>Stress management and relaxation</td>
<td>Reminders (e.g. sleep, stress,</td>
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<tr>
<td></td>
<td>Sleep routines</td>
<td>avoiding stimuli)</td>
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<td>Resting, avoiding overexertion</td>
<td>Stress management support</td>
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<td></td>
<td>Avoiding foods or stimuli (e.g. flashing lights)</td>
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<tr>
<td>Symptom tracking and reporting</td>
<td>Seizure log</td>
<td>Symptom and side-effect monitoring</td>
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<td>Seizure log</td>
<td>Symptom and side-effect monitoring</td>
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<tr>
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<td>Symptom and side-effect monitoring</td>
<td>Symptom and side-effect monitoring</td>
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<tr>
<td>Treatment management</td>
<td>Making and going to appointments</td>
<td>Appointment reminders</td>
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<tr>
<td></td>
<td>Communication with neurologist</td>
<td>Driving to appointments</td>
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<td></td>
<td>Making medical decisions</td>
<td>Attending appointments</td>
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<td></td>
<td>Finding information on symptoms,</td>
<td>Discussing and supporting</td>
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